

Enhancing the Quality of Life of People with Disabilities A Strategy for Portugal



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Technical Information

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Chapter 1.
Introduction

Over the last decades, Portugal has seen extraordinary progress in terms of policies and practices for people with disabilities. Specifically, when Portugal joined the European Union new resources came in and new dynamics were developed, which consisted in opportunities taken up by the country, both at the level of public policies and the dynamics of civil society.

In spite of all the progresses made and of the accumulated experience, there is still the need for investing in the weaker areas and in developing the potential of the remaining areas, within an approach of adapting to the needs of the citizens, of solving their problems and in an effort of optimising the resources involved. We now have the appropriate conditions for a new impulse and for a renovated systemic vision that may lead the country towards a new cycle in this field of activities.

On the other hand, this new cycle may also benefit from renewed models of approach and analysis regarding the subject of disabilities, of new conceptual and political references, with significant impact relating to the concepts and semantics, as well as the perspectives and social attitudes regarding this phenomenon. On the contrary, the amount of knowledge generated in the country on the issue of disability and impairment remains significantly low, mostly originated from experiential knowledge, non-systematic, non-structured, non-integrated, and of difficult access. So, it must be further developed and made more accessible, as the knowledge and characterisation of the phenomena are the corner stones for developing intervention policies and programmes, being fundamental conditions for their success.

Within this framework of strategic concerns, and with the intention of contributing towards the development of policies that may favour people with disabilities in Portugal, the Study “Modelling Social Inclusion Policies and Practices for People with Disabilities in Portugal”, from where the present report was generated, aimed at five main objectives:

- To use the knowledge generated in assessment studies carried out in Portugal in the last years, by systematising them, in order to generate guidelines for supporting decision making in the short term.
- Through a survey, to collect, organise and analyse data related to the characterisation of the Portuguese population with disabilities, by identifying levels of incidence, correlations and impacts, in order to promote knowledge and to support decision making.
- To analyse biographical pathways of people with disabilities, identifying possible correlations with the existing policies and programmes.
- To model policies, practices and their respective management, supporting optimisation of results and resources, through comparative inventorying of conceptual, intervention, financing and management models.
- To promote a deeper and more systematic strategic reflection on the social

inclusion of people with disabilities, by mobilising and involving researchers, directors and effective workers.

As a main outcome of the Study, the present report “**Enhancing the Quality of Life of People with Disabilities – A Strategy for Portugal**” is considered a fundamental reflection from the work developed, presenting the results of all the research that was made, discussing the options and formulations of conceptual and policy nature, as well as making proposals of policy and strategy models, and proposals for their management, adapted to the specific situation of the country and to the challenges it faces.

This path was started by analysing the situation at several levels, which is presented in chapters 2 to 6. Theoretical developments are recorded, concepts are made operational, target-populations are characterised, and the state of the art of the sector in Portugal is defined.

The objective of Chapter 2 is the analysis of the relationship between **Impairments, disabilities and social inequalities**. This chapter describes how people with disabilities were the object of prejudice and discrimination along History and in different cultures, and it also shows how negative judgement and inferior treatment associated to personal characteristics of this population varies in forms and magnitude, from where the development of inequalities between persons with and without disabilities are consequences, and with the exclusion of those with disability from society life. The phenomenon of “double disabilities” is also addressed, when unequal treatment following from disability and impairment coexists with other inequalities. It is argued that social injustice present in the different forms of unbalance which were analysed, demands an effective solidarity among the different social movements, not just as an ethical principle in and of itself, but as a condition for efficacy, as well as specific social policies with a common basis.

In the following chapter (Chapter 3), the **evolution observed in the conceptual reference models**, is briefly presented while explaining the underlying paradigms and theoretical perspectives, with special focus on the transition from the medical model to the social model, and upon the bio-psychosocial model, as an integrating approach for the former ones. Analysis of the different models led to the proposal that a quality of life model be adopted as a conceptual structure for organising policies and interventions in this domain. In this chapter, the evolution of concepts and terminology in this field is also analysed, and a proposal for delimitating the concept of disability and impairment and for making it operational is also explained, while the main operating concepts are systematised.

Due to its significant importance, for delimitation of the object, and as for its consequences for formulation of policies, a whole chapter (Chapter 4) was dedicated to the **International Classification of Functioning, Disability and**

Health (ICF) as a framework for disability policy design and deployment.

In this chapter, the reasons that sustain the adoption of the ICF as an operational framework for the development of a National Strategy for Disabilities and Impairments are characterised. In a different ambit, but not less important, an analysis of the applicability of the ICF is also carried out as an organising reference for assessing individual needs.

In Chapter 5, and with the purpose of contributing towards the **characterisation of people with disabilities in Portugal**, the data from a survey carried out before a representative sample of the population residing in Mainland Portugal, aged between 18 and 70 years, is analysed. With this purpose, the ICF was used as an analytical reference, from the design of the survey to the interpretation of the data, which makes this characterisation pioneer work and which conveys a new image of the reality. From the set of characterising indicators, we would highlight the global profile of this population – predominantly a universe of female, adult and elderly, with very low levels of education – significantly lower than the national average. These persons were globally excluded from the labour world, in which the few that ever had any work experiences show that their professional integration was made in positions with the least qualifications and which lead to intergenerational pathways that replicate social classes with the least resources or descending pathways of social mobility, and which family income is concentrated at levels close to the national minimum wage.

As for the correlations between rehabilitation policies and life pathways, from the total number of persons with disabilities in need of support from the existing services of the rehabilitation system, the rate of coverage is of about 30% and falls mostly upon part of the population mainly of young males, which developed/acquired changes of functions at birth, and which primarily show changes in mental functions, in sensory multi-functions and of speech, physical and mental. This population presents different characteristics comparatively with the population that was not benefited from any services or support from the rehabilitation system: it has higher academic qualifications, even though it has lower integration in the labour market, and presents greater levels of satisfaction as for their life in general, as well as for their material and financial situation.

In the following chapter (Chapter 6), an analysis is carried out as to the way the **rehabilitation system evolved in Portugal**, characterising the **state of the art**. A path of effective progress for the Portuguese rehabilitation system in the last decades is confirmed, namely in terms of policy and ideology, programmes and measures, support, response services and structures, as well as for the target public which it has been considered. Within the scope of the same dimensions, the path to follow is then presented, in which the main challenges for the future are identified.

After having analysed the national dimension, the **reform lines of the rehabilitation policies at an international level** (Chapter 7) are then explored. From the identification of the main international policy instruments, from the analysis of the emerging or of the existing conceptual models and from the experiences from other countries, a set of development trends are then presented. As far as financing rehabilitation services, some current dilemmas are presented, regarding the support and the Strategy of the European Social Model, then moving on to the identification and systematisation of some of the main trends as far as the evolution of rehabilitation services and of the financing models, as well as the requirements demanded by their practical implementation. The political and legal framework for social services of general interest is also addressed, within the scope of which disability-related services are integrated.

The preceding chapters bond for the presentation of proposals and guidelines for a policy model and for a strategy for Portugal. Chapter 8 presents a model of strategy for Portugal – **A policy model for enhancing the quality of life**. It starts off with the identification of a vision: The vision that **by 2025** Portugal shall ensure that all people with disabilities shall have **equality of condition**, shall be valued, shall be offered **opportunities** for enhancing their **quality of life** and shall be ensured full participation in an **open, inclusive and decent society**. This sort of vision, which might seem to aim at an ambitious and far distant goal, will have to be fulfilled through the definition of strategic goals and policy guidelines, for which specific proposals are presented, and put into practice by specific plans containing appropriate actions, of which some examples are given.

Considering that the success of a policy model is strongly determined by its governance, the **governance model for such strategy** (Chapter 9) formulates and presents the main dynamics for its operation, defines responsibilities, how to monitor and control progress of its implementation, and how to carry out results and impact assessments. Dynamics governance and the various levels of responsibilities are presented. Lastly, the proposed strategic options are explored in terms of financing models – as strategic element for change – as well as the structure for the network of services.

All research and proposals presented herein, developed from the joint work of a team of experts, both National and European, with the involvement of an enlarged group of representatives of institutional stakeholders, intends to be a first contribution towards the definition of a strategy for a generation, which can then be developed according to the principles of legitimacy and participation used for its definition, involving public discussion and enlarged participation of the different stakeholders. Thus, it should be read as a conceptual contribution and as a working basis, so that, should the main guidelines of the proposal be accepted, a strategy and action plan can be stabilised, containing definitions of goals and results to achieve, of actions to undertake, and of resources to prepare.



Chapter 2.
**Impairments, disabilities and
social inequalities**

The history of people with disabilities is an important chapter of the history of social inequalities.

As far as we know, people with disabilities have been the object of prejudice and discrimination along History and in different cultures, even when the negative judgement and inferior treatment, associated to personal characteristics of this population, vary in form and magnitude.

Thus, prejudice and negative discrimination are powerful factors for generating inequalities among people with and without disabilities, and for excluding those with disabilities from society life.

These processes can be confirmed in a brief historical glimpse (VEIGA, 2006; ABBAS, 2003; RAVAUD & STIKER, 2000A, 2000B; BARNES, 1999; BIANCHETTI, 1998; WINZER, 1997; FOUCAULT, 1993, 1991; LUCKIN, 1986).

It is very likely that in recollecting societies, where Man was deeply involved in the struggle for survival, many people with disabilities were just abandoned to their fate and eliminated from the groups where they took birth, when it was considered that they did not contribute towards the vitality of the group as a whole.

The existence of writing and of laws, in the first agrarian societies, allow us to observe clear signs that the development of magic and of the distinction between good and evil, in many cases, led to considering these people, at that time, as “impure”, i.e. as possessed by evil spirits.

Focussing on History in a closer cultural period, we can see that in Greek and Roman Antiquity, military investment, hedonism and cultivation of the perfection of the body, induced a reinforcement of the symbolic cleavage between “pure” and “impure”, and led to the dissemination of eugenic practices of eliminating new-borns that did not fit into the dominant standards of perfection, and to the remission of individuals with disabilities to unvalued social functions and to marginal roles.

With the propagation of Christianity, disabilities were considered as divine punishment and the “impure” ones started being called “sinners”. According to the Christian doctrine, individuals with disabilities would be elected as objects of charity, and a status of stigmatisation and dependence was established. Organised support to this population became institutionalised, which would extend to their enclosure in monasteries, hospices, asylums, and so, into the development of a logic of spatial segregation of these persons.

Such stigmatisation and spatial segregation also resulted in the institutionalisation processes resulting from practices of social control carried out by the European Nations of the time and from the discrimination that this population was the object, in the laws of these States. All of this contributed decisively to keep people with disabilities at the margin of public space and of the productive process during the Medieval Age, during Feudalism, and during the development and consolidation of the Nation States.

The growing process of rationalisation of social life, associated to the emergence of modernity, and particularly, the development of Science, allowed to clear the dominant image of impaired and disabled persons as being “sinners”, but then to immediately include them in the symbolic category of “dysfunctional” persons, in which this representation would then be further reinforced with the emergence of industrialisation and capitalism, following the drastic increases in social differentiation and specialisation, the reinforcement of social importance, of the working sphere, and of the imperative of the accumulation of capital.

The scientific and technological approach to disabilities in clinical practice, seeing it strictly as a personal tragedy, plus the emphasis in maximising profit and productivity and some modern ideologies, promoting human perfection from partial cultural criteria as a consequence are going to lead to a social and administrative definition of disability as an individual problem with static status, something caused by a deficit and to the maintenance of logics of institutionalisation and spatial social segregation, now with a medical basis and to the (re) emergence of eugenical type of movements during the 19th Century and beginning of the 20th Century, as the case of Nazism.

Obviously, these processes do not exhaust the position of disability and impairment in History. We can still identify concerns, social standards and institutional and individual practices inclusiveness, of these persons at different times and in different socio-cultural contexts.

There are several cases of known tribal communities in which signs of exclusion of people with disabilities are not seen, in spite of the precarious conditions of survival (BARNES, 1998; SCHEERENBERGER, 1984).

Magicians, witches, witch doctors tried all along History to integrate these individuals in the life of their societies, even if mostly through investing in their “cure” thus exhibiting a type of relationship with physical and psychic differences which generally involves a prejudiced vision of such differences.

Major religions such as Confucianism, Buddhism, Judaism, Christianity or Islam have had an important moral role in social rejection of infanticide, in preserving the lives of people with disabilities and in their physical protection, even though they do not promote any rupture with prejudice related to this population, nor their rehabilitation, or their independence.

The advancements in Medicine, the implementation of the modern States and the prevalence of the illuminist goals, are going to enable health care and rehabilitation services, civil and political rights, social protection and formal education to this population, but all of this still fulfilled through a segregation type of model, without an actual concern for the issue of their individual and social autonomy.

With the Welfare State, mostly during the first half of the 20th Century, some of the rights of these persons are extended, specially their social rights, but their

justification within the social security system through financial support allowances, and their preservation in a condition detached from work, are going to generate a culture of dependence for this population, which contributed objectively towards the replication of the vulnerability and social exclusion of people with disabilities.

We can say that equality through difference as full autonomy and citizenship only became directly targeted and actually included in the political and social agenda, when the issues related to disabilities stopped being an issue upheld by only professionals and by political actors and started being an issue of the persons with disabilities themselves. The political organisations and the social movements of people with disabilities, which burst towards the end of the 1960s, rejected the existing individual model in terms of vision and approach to disability and founded what became known as the “social model”, in which the goals and contents are going to be presented in depth in the next chapter, but which are mostly characterised by the principle that disabilities should be interpreted not just as a personal issue, but also, and above all, as a social and political one (FINKELSTEIN, 2001; BARTON 1993; OLIVER, 1992, 1991, 1986).

The existence of negative prejudice against this population in contemporary societies is a topic that has been object of some debate. Instead of prejudice, one often talks about ambivalence, arguing that the type of relationship that individuals in general have with people with disabilities result from conflicting values: disabilities are socially underestimated, but this does not necessarily imply that people with disabilities are equally socially underestimated. These people usually invoke intense feelings of sympathy and altruism and the reaction they trigger in others significantly depend upon the contexts (SÖDER, 1990).

In face of what has been said, and in spite of the political, scientific and social advancements identified previously, and referred cultural ambivalence, which has specific incidence in face-to-face relationships, it is important to add that, according to the information currently available on the global social condition of people with disabilities, solidarity, charity, civic and political rights and the social services made available along History have not been enough to cancel inequalities, social injustice and exclusion related to this population.

First of all, because today’s world is different in what concerns the distribution of disability. There is a clear greater percentage of individuals with disabilities in the less developed countries, when comparing with the developed ones, which difference in general corresponds to a significant inequality in access to medical care and social measures.

Thus, development clearly represents a positive factor, both for prevention, as well as in terms of the types of care that may decrease the incidence of disability. This does not mean that development is a beneficial factor just in one direction, in what concerns disabilities.

There is evidence that in more developed countries, unregulated pressure for economic effectiveness and efficiency, environmental pollution, some lifestyles and consumption patterns, and a type of technological development not sufficiently controlled, trigger specific factors that generate disabilities and impairments, such as labour accidents, intoxication, poor nutrition, unforeseen negative side-effects of some medication, etc. (ABBERLEY, 1987).

Even the increase of life expectancy, by generating significant growth of the elder population, is a direct cause of increased disabilities associated to aging. The concept of “life expectancy with no disabilities”, that has been used more and more as an indicator of development and quality of life, reflects, to a great extent, the need to use new references adjusted to the present demographic and social trends.

If we analyse contemporary societies, now through what goes on in different areas of social life, we can see that inequality remains in a systematic way, between people with and without disabilities. These inequalities are present in the relation between work, and leisure and free time, between schooling and literacy, between citizenship and civic and political participation, are present in relation to housing, to transportation, to public services, to health care, to life expectancy, etc. This list goes on into areas of more individual and personal nature, with the development of a family, of affection, of sexuality, of friendship, etc.

Work is one of the most important areas where obvious inequalities remain, amongst individuals with and without disabilities. The degree and type of participation in the labour world are fundamental dimensions of social life, as the participation in production are associated to the basic processes of development of social identity, levels of income, standards of consumption, social recognition, references of civic and political participation, etc.

What can be seen is that people with disabilities keep being discriminated, first of all in terms of job access. The rates of activity and employment among this population are generally lower than the national average and by significant differences. But even when they do have a job, there is generally an under-representation of these individuals in situations of sub-employment, when compared to those without disabilities or impairments.

Sub-employment covers a large set of very distinct aspects. For instance, it is present when capacities are under-used. But also when there are involuntary situations of part-time jobs. We can also speak about subjective sub-employment when the labour situation is perceived by the person himself/herself as being of sub-employment. Here we can also include those situations where there is a misuse of qualifications.

Besides inequalities in access to a job and in sub-employment, we can also see an over-representation of people with disabilities in unpaid jobs, in the lowest levels of income and wages and in unqualified jobs, or the replication of some

aspects of the outplacement condition regarding the global labour market in situations of sheltered jobs (ABBAS, 2003; BLANC, 1999; BARTON, 1993).

The level of education is another very relevant dimension of social life in our days, as it is a large spectrum cultural resource, affecting the development of citizenship, of civic education, of scientific and technical knowledge and of social and relational competencies, which thus have crucial importance as well in the labour market and in professional life. And just as in the labour world, inequalities remain as well among individuals with and without disabilities in what concerns education, where the former are usually under-represented not just in higher education, but also at the mandatory levels of education.

Social and political participation of people with disabilities, through the use of information, through discussion and through decision making, upon issues of the society where they live and upon the problems that actually concern them in a direct way, remains very small fragmented and in general set at a subordinated or limited level within an environment of acquiescence and paternalism (BARTON, 1993; OLIVER, 1992; MORRIS, 1991). This participation deficit goes on in terms of the most insignificant presence of individuals with disabilities in top social positions in terms of decision making and responsibility.

Naturally, the population with disabilities is not socially homogeneous (CAPUCHA, 2005A). Differences in terms of origin and social status both of these persons and of their family members determine different degrees and types of discrimination and of social vulnerability (ALLEN, 2007; ABBAS, 2003; BARTON, 1993; ABBERLEY, 1987).

Prejudice and discrimination increase, for instance, when people with disabilities belong to the female gender or to any ethnic or sexual minority (BARTON, 1993; MORRIS, 1991; ABBERLEY, 1987).

Actually, there is a significant association between disabilities on one hand and social classes, on the other. People with disabilities are often over-represented in classes of lower resources, specifically among less qualified workers and manual work. This relation is particularly relevant in what concerns economic conditions: when compared to the general population, the population with disabilities clearly live in conditions of need, which is visible in the fact of earning lower incomes, of possessing less material assets, of having greater debts, etc. The existence of disabilities is generally associated to the descending pathways of social mobility and impoverishment (ALLEN, 2007; JENKINS, 1991).

The relationship between disabilities and poverty is also a recurring topic. And it is a bi-univocal relationship, which reveals the existence of a vicious cycle of poverty and disabilities. Disabilities are factors of social vulnerability and impoverishment, as mentioned above, mostly due to prejudice and to discrimination, which in turn generate social exclusion. In fact, poverty is, in and of itself, a factor that generates disability (CAPUCHA, 2005B; BARTON, 1993; OLIVER, 1991), due

to the characteristics it usually contains: the environment in which people socialise, economic deprivation, information deficits, poor conditions of living and housing, lifestyles and consumption patterns involving risk behaviours, lack of prevention practices, higher and persistent incidence of health problems, drug addiction and alcoholism, little incidence of health care practices.

In 1755, within an historical context in which inequality was globally considered as something natural, Jean-Jacques Rousseau stood out by establishing the distinction, in his *Discours sur l'Origine et les Fondements de l'Inégalité Parmi les Hommes*, between natural or physical inequality – established by Nature and which consists of differences in terms of health, body strength and the qualities of the spirit or the soul, and political inequality – that which concerns the differences in terms of wealth, power or prestige, and which depends upon a convention, being established, or at least authorised by Man.

Presently we are far beyond Rousseau, as it is well known that physical and psychic differences, called “natural”, depend upon social and political factors. But disabilities is an autonomous factor in the production of social inequality, which means that even people with disabilities coming from social environments with greater resources and with better socio-cultural integration live experiences of prejudice and discrimination.

In general, this means that inequality among people with and without disabilities are articulated with other forms of inequality, and that the effects of all these different types of inequalities are cumulative.

The approach to inequalities that lead to social exclusion of individuals with disabilities can not be done without analysing other forms of prejudice and discrimination, at the risk of losing the dimension and the processes of reinforcement among the different factors of social exclusion.

The existence of cumulative effects of the different types of inequalities means that fighting social injustice, present in each form of inequality calls for actual and effective solidarity among the different social movements not just as an ethical principle, but as a condition of efficacy. Thus, it demands specific social policies focused upon different forms of social inequalities but with a common basis.



Chapter 3.
**Evolution of the conceptual
reference models**

CONCEPTUAL MODELS

From the medical to the social model

When addressing issues related to rehabilitation and incapacities, it is important to understand social changes in the perception of incapacities over time. Since the 1960s, there has been a growing awareness on the side of politicians, legislators and social researchers, that the issue of incapacity can not just be considered from a strictly individual perspective (BARNES & MERCER, 2003). Recent data suggest that there are 50 million persons with disabilities in Europe and 500 million in the whole world and it is expected that these figures shall rise significantly in the next decades, both in the countries considered as developed countries as well as in developing Nations (IDF, 1998). This is due to a wide range of different factors, such as progress in Medicine, aging populations and intensification of the pace of social and technological change (COLERIDGE, 1993; INGSTAD, 2001). All these factors have economic, political and cultural implications for the national governments and for international bodies such as the European Union and the United Nations. A growing concern is centred on increased costs with rehabilitation programmes, recognised as scientifically appropriate and with socially adjusted responses to the types of problems felt by people with disabilities (STONE, 1985; ALBRECHT, 1992; SANDVIN, 2002).

Conceptual developments in intervention policies and in the organisation of models of intervention, within the context of rehabilitation and social inclusion, have been reflected in the way the different social players equate and analyse the issues connected to disabilities. Within such evolving framework, we can see that disability was equated as an issue of the persons with disabilities themselves, directly caused by disease, by accident or by another health condition, possible of being improved through interventions exclusively centred on the individual, such as rehabilitation. With this understanding, the approach of intervention policies was focused on the acknowledgement of special needs through the creation of special services. These services were based on the creation of a network for providing specific care to people with disabilities, thus favouring institutionalising mechanisms. Another feature of this initial stage of conceptualisation of disability was based on focusing all power and control of intervention processes on the technical and professional staff in the sector. From the point of view of the surrounding cultural environment, there was reinforced stigmatisation and prejudice towards people with disabilities, through the message of it being impossible to integrate the differences in terms of social structures and of services available in the regular systems, materialised by the different types of disabilities. From the focussing point of view and the policy objectives, these

were centred on the individual, being that the main goal was to activate compensation mechanisms capable of alleviating the effects of the incapacities.

Additionally, we must mention that one of the characteristics of this period was that the *locus* of responsibility for such policies was based on the model of the Welfare-State of the Ford period. Traditional social policies were based on medical orientation and on the interpretation of the nature of disabilities and so in the whole set of characteristics that have been listed; the elements that integrate the medical model ⁽⁰¹⁾ of approaching disability have been identified.

International documents from the World Health Organisation (WHO) and the European policy documents progressively started to emphasise disability, not as an attribute inherent to the person herself/himself, but as a result of the interaction between the person and the environment including its physical structures (the design of the buildings, the transportation systems, etc.), the social relations and the social constructions and beliefs which lead to discrimination of certain people. In this way, disability became a relevant issue for social policies, as the consequence of adopting a model which favours the adaptation of the context to the persons and so its focus is not any more exclusively the individual component and starts including the relationship of the person with the environments, the life contexts as well as the obstacles and social barriers that emerge from such interaction. In this way, participation of all citizens in the most diverse contexts of social life becomes an issue of rights and equality of opportunities.

From the social policies point of view, we can see two different focuses in the inclusion speeches and proposals. The first one works inclusion through increasing citizenship, emphasising the dialogue of the right to interact and the right to social participation through social networks, in building the collective project. The second one focuses on fighting exclusion as an element aimed at including the underprivileged public in the labour market. In this case, the focus of inclusion has its epicentre in professionalisation and the capacity of working and finding employment. In parallel, to these focuses, there is the underlying need of eliminating environmental barriers (physical, psychological and sociological), as a necessary condition for full participation of people with disabilities in society, in a logic of equality of opportunities for all.

This conceptual development in the way disability is addressed made it possible that, for the very first time, the different needs of people with disabilities were acknowledged as being the object of response from the regular services e structures of society. This fact is based on the reconfiguration of the models of inclusion and collective capacity of all social players which directly or indirectly,

(01) The available literature in this area defines the medical model as a social and historical point in time of approaching the issue of disability centred on the individual aspects of the person.

contribute towards exclusion/inclusion of people with disabilities. In this way mainstreaming perspectives are structured, which have been institutionalising the implementation of specialised services based on a consulting logic and based on the community structures and services. This rupture with the medical model, in the way disability is conceptualised, implied that policies started to be aimed at removing barriers and with the full participation of people with disabilities, instead of “complicating” the person and just focusing only on her/him. We can confirm this approach in the development of regulations, on the design of buildings and on the transport infra-structures, in order to prevent the construction of disabling situations and contexts and to reduce the existing barriers, among many other manifestations.

From the point of view of the cultural environment, acknowledgement of differences started to emerge, as well as the relevance of adopting policies that may foster integration of diversity. Within this scope, policies progressively started to intentionally bring about changes in the patterns of attitudes and behaviours, in the way that citizens understood and perceived people with disabilities (named as symbolic policies), focusing on changing the inhibiting elements of participation into facilitating factors. In the same way, in spite of the fact that there are still no coherent and consensual guidelines for defining the category of people with disabilities/without disabilities, symbolic policies start to feel the need to frame this delimitation and definition in order to guarantee its success and efficacy in transforming the symbolic representations of citizens. The set of characteristics enumerated, as well as their constituting elements, have been designated by researchers of the social model, in opposition to the characteristics of the former model centred on the individual deficit, known as the medical model. However, it should be mentioned that the type of approach centred on the individual is not exclusive of the medical model rather represents a social-historic approach.

Nevertheless, the fact that in our days the medical model was the object of a deep transformation, Table 1 intends to highlight the main points of rupture between the traditional medical model and the social model seeing as the predominant choice for one or the other model implies a radically different conception of the different typologies of policies, as well as the definition of different goals and results regarding the inclusion of people with disabilities.

TABLE 1. COMPARATIVE ANALYSIS OF THE TRADITIONAL MEDICAL MODEL VERSUS THE SOCIAL MODEL, REGARDING THE STRUCTURING DIMENSIONS IN ORGANISING THE CONCEPTUAL FRAMEWORKS OF INTERVENTION (SOUSA, 2005, ADAPTED)

	Medical model	Social model
Problem	Impairment/dependence upon other people	Inappropriateness of contexts for people
Origin	In people	In society
Focus	The person, their limitations	Relationship person/context, social barriers
Ethics	Assistance	Rights Equal opportunities
Goals	To rehabilitate, to cure, to treat	To empower To eliminate barriers/to promote compatibility
Approach	Special needs Specialised services	Different needs Regular services
Services	Institutionalised Care Network	Support, based on the community
Power, control	Professionals	Customers
Culture	“Disabling” Maintenance and reinforcement of disability	Acknowledgement of inclusion and diversity
Policy goals	To compensate individuals for their impairments “To mitigate the situation”	To promote rights To provide resources and competencies in order to identify and to eliminate personal and social barriers
Policy focus	On individuals On people with disabilities	On the social group On the global population
Responsibility	Social policy Welfare provision	Transversal policies Socially active policies

The social model of disability appeared in the 1960s in the United Kingdom, as a reaction to the biomedical approaches. The basic premise of the social model is that disability should not be seen as an individual problem but rather eminently as a social issue, transferring the responsibility for the handicaps of people with disabilities to the incapacity of society in being able to foresee and to adjust to diversity (OLIVER, 1990). In the 1970s, around the social model of disability appeared UPIAS (The Union of the Physically Impaired Against Segregation), one of the first organisations of people with disabilities in which the objectives were eminently political and not just for assistance purposes, as was the case of the institutions created in the two former centuries (UPIAS, 1976). The theoretical starting point of the social model is that disability is an experience resulting from the interaction between the body features of the individual and the conditions of the society in which he/she lives, i.e. from the combination of limitations imposed by the body with some type of loss or reduced functionality (injury) and a surrounding social organisation little sensitive to body diversity. Originally UPIAS proposed a definition that expressed the effect of exclusion in the creation of disability: “injury: lacking part or all of a limb, or having a defective limb, organ or mechanism of the body’ and disability is: ‘the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976:3-4). The initial emphasis in physical limitations was immediately reviewed and with this a major debate was started on the limitations of the type of vocabulary used to describe disability. The intention was to highlight that, necessarily there was no direct relationship between the injury and disability, transferring the debate of the health issue to the field of social and political organisation. Injury would be a body feature, just as the specific gender or colour of the skin, whereas disability would be the result of the oppression and discrimination suffered by people, due to a society that organised itself in such a way that it did not allow their inclusion in current daily life. It is therefore possible for a person to have injuries and to not experience disability, depending on how much society is adjusted to incorporate diversity. As exemplified by Morris (1997), to not be able to walk is the expression of the injury; disability consists on the inaccessibility imposed upon people who use wheel chairs. The result of this revision in the semantics of concepts was a radical separation between injury and disability: the first being the object of the discussion on health, whereas the second is an issue of rights and social justice and therefore mostly normative.

If for the medical model injury would lead to disability, for the social model the social systems would lead people with injuries to experience disability. In summary, the medical model identifies the person with disability as a person with some type of incompatibility for society; the social model, on the other hand, reverses

the argument and identifies disability as the inaptness of society for including all people, managing their diversity in an inclusive way. In general, definitions based on the medical model demand a great distancing from the standards of normality in order to consider a person as being disabled. The criterion used for defining disability usually have, as a reference the complete loss of certain organs or functions. Identification of disability is made considering the isolated characteristics of these organs and functions and comparing them to limits established for each one of them. Within this framework of intelligibility, there are criterions that establish, for each compromised organ of function the limits of disability, such as for example, minimum levels of visual acuity, hearing capacity, etc., which can be assessed in an isolated way each one from the other, as well as separated from the needs imposed by the social characteristics of each person.

Combining the existence of a health condition well below an abstract standard of normality with the persistence of such condition over time allows the medical approach to distinguish between disease and disability. Many diseases are understood as temporary situations. This way, even though having a health condition below what is determined by some criterion of normality, people who are sick may not be considered as experiencing a disability within the medical approach, as their reduced capacity is just temporary and does not allow the definition of an identity. The contrary is also done in order to separate disability from disease, however with a more sophisticated argument. If disability is an irreversible situation, it is perfectly possible to redefine the concept of normality in order to adjust it to the persons' permanent condition. Blindness, for instance, becomes a normal condition for a blind person and so it does not make sense to classify such person as sick. So, in this context, a person that can not see because she/he has a serious inflammation in the eyes, he/she is a sick person, whereas a permanently blind person is a disabled person. As the acknowledgement of the "disabled society" is as much or even more important for the debate on public policies than the identification of the "disabled person", the concerns with identity in the social model are quite distinct from those of the medical approach. Abberley (1987), for instance, does not insist in the distinction between disability and disease and practically ignores the rule of persistence of the injury over time in order to identify persons with disabilities, which was such an important criterion for legislators of social policies in the 1980s, which used it systematically for counting populations in several countries around the world. The logic of the social model does not acknowledge such distinction, mainly because it understands that the adjustments required by society for it to consider that the diversity of disability is independent from how much time a given body condition is going to remain. After all, if a person in a wheel chair while recovering from fractures in the legs needs the same adjustments in the transportation system as a person permanently incapable of walking, why separate them into different

groups? By not acknowledging that people who are sick also experience disability, the medical model excludes from the scope of public policies a major portion of the population that actually also needs them in particular a significant part of the elderly population. To not use the same distinction method used between disease and disability is a resource of the social model to avoid this type of exclusion. The obvious consequence of the definition of the social model is that research and public policies aimed at disabilities, can not just be concentrated on the body aspects of individuals in order to identify disability. Furthermore, by separating disability from injury, the social model opens up enough room to show that in spite of the diversity of injuries, there is a factor which unites all different communities of people with disabilities around a single political project: the experience of exclusion. According to Oliver (1990, adapted), “all disabled persons experience disability as a social restriction, whether such restrictions occur as a consequence of inaccessible environments, of questionable notions of intelligence and social competence, or from the incapability of the population in general to use sign language, due to the lack of Braille material or due to hostile public attitudes from people with no visible injuries”.

In the mid 1990s, feminist movements launched an argument with deep implications for public policies: the experience of disability within the family environment, presents implications at the level of gender. By showing that disability is followed by reorganisation of the family in order to care for the person with disability, the feminist movements highlighted that it is not just people with some kind of body restriction that need attention from public policies. Considering that care takers are mostly women, due to the sexual division of labour, disability, when understood as a phenomenon with family implications has a gender bias. For instance, it is women that step out of the labour market in order to care for disabled persons, for children and for elderly persons. In the case of elderly men, this division includes an overlapping of gender and age, due to the typical pattern of family arrangement, in which elderly women care for these men. Such stepping out from the labour market has many implications for women, such as the absence of support services and of general support for women at an economically active age and such fact can not be left out from public policies (BARTON & OLIVER, 1997).

By the end of the 1990s, some of the arguments of the social model of disability were reviewed. The motto “Limitations are social, not of the individual”, which was used to demand better conditions for people with disabilities so that they could be more independent started to become more relative. A long tradition of feminist philosophy criticised the value of absolute independence, showing that interdependence through the care offered to the dependent ones, is a basic element of life in society and that in many disability cases, it can not be avoided at all. Therefore, public policies should not just try to promote the autonomy of people with disabilities but rather create favourable conditions so that support could be implemented.

The bio-psychosocial model

The bio-psychosocial model emerged from acknowledgment of the limitations of the biomedical models to provide an integrated vision of human functioning within the framework of each others relationships with their life contexts.

From the article of Engel, published in Science Magazine, in 1977, a bio-psychosocial model emerged, trying to focus its object of study in understanding human functioning, in the light of ones interactions between the biological, the psychological and the social dimensions.

Engel postulated that each system (biological, psychological and social) can affect and be affected by any other system, which supposes a systemic and interdisciplinary approach in the interpretation of human functioning.

TABLE 2. COMPARATIVE ANALYSIS OF THE MEDICAL MODEL AND THE BIO-PSYCHOSOCIAL MODEL

Medical model Closed and linear model	Bio-psychosocial model Open and interactive model
Human health is mostly seen in terms of its biological component.	Health results from the complex interaction between several factors: organic, psychological and social.
Health has an impact upon the person.	Health, has significant impacts upon the person, the family, the community and the state.
Someone's health condition can be the object of diagnosis and treatment.	Quality of human functioning requires a continuous and holistic approach: from prevention to rehabilitation.
Medical doctors and health professionals.	Specialised staff and all relevant players for the quality of human functioning, involved in the system of relationships of the individual.
Autonomous system centred on hospital institutions.	Open system interdependent with the community.

The bio-psycho-social approach is expressed in the latest works of the World Health Organisation for redefining disability: namely the International Classification of Functionality, Disability and Health, formerly known as the International Classification of Impairments, Disabilities and Handicaps or ICIDH2 (WHO, 2002).

This redefinition is a combined attempt to integrate the medical model and the radical socio-political interpretation of the social model, as the result of its rejection by people with disabilities and by organisations and partners within and without the scientific community (DRIEDGER, 1989; OLIVER, 1990; BARNES ET AL., 2002).

In accordance with its predecessor, the ICF maintains the three part construction. The first level: disability, in the original, is related to the “functions and structure of the body”. The second level, which formerly was impairment, is now referred to as “activity”; and the third: handicap, appears as “participation”. However, and in spite of the intense debate around the meaning of disability, the concept is preserved as a global term for the three levels of difficulty to function.

In this present scenario and contrasting with the International Classification of Impairments, Disabilities and Handicaps (ICIDH), the new formulation is presented as a universal classification of human functioning. People connected to the advocacy initiatives defend that this present configuration offers a complete intelligible framework for the functional aspects of health experience. According to this approach, disability is the result of the interaction of the person’s characteristics and the characteristics of the physical and social environments. In this way: “rather than being a classification of persons with disabilities, or even of the problems that they may experience, the ICIDH2 [ICF] is a classification of functionality at three levels, understood in neutral terms” (USTUN ET AL., 2003).

Within the framework of rehabilitation, the bio-psycho-social approach is a synonym of the change of services centred on institutions into services and support centred on the community. In this way the emphasis is placed on integrating people with disabilities in mainstream society. The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993), of the United Nations (UN) specifically declares that all States should provide rehabilitation services. However, this guideline recommends to go beyond just the “initial medical care” and to include “a wide range of measures and activities from more basic and general rehabilitation to goal orientated activities” (UN, 1993). Even more significantly, all rehabilitation services “should be available in the local community where the person with disabilities lives. However, in some instances in order to attain a certain training objective special time limited rehabilitation courses may be organised, where appropriate, in residential form” (UN, 1993).

Quality of life model

Emergence of the construct and fundamental theoretical models

Quality of life is a highly disseminated concept in social and political sciences (GUILLEMIN ET AL., 1993; GUILLEMIN, 1995A, 1995B; MATHIAS ET AL., 1994). However, as a scientific concept it may reveal itself as ambiguous, considering the emerging difficulties for its definition (WOLFENSBERGER, 1997).

The interest for quality of life also appeared connected to the system of social indicators (CUMMINS, 2000; RAPLEY, 2003), when formerly an essentially economic type of approach prevailed, analysing economic growth of the different societies through the evolution of the respective Gross Domestic Product (GDP) or through income *per capita*. This way, Evans (1994) explains that one of the main reasons for studying the quality of life of a given population was related with the limitations of these indicators. At the end of the 1960s, it was acknowledged that in order to be able to compare countries, something more than just the gross economic indicators such as the GDP, were required. The social indicators, or measures reflecting the level of social development of the country and not just its economic development, were the alternative proposed.

According to Evans (1994), one of the limitations of the approach of social indicators, is based on the fact that they do not solve all the issues, in the sense of actually assessing quality of life, because even though they do offer information on the cultural/administrative units (city, country), they supply very little or hardly any information on the quality of life of individuals inside the unit. This increased the interest for assessing quality of life also perceived as the so called subjective quality of life, by finding subjective indicators for the construct. Many researchers have found inconsistent correlations between the objective social indicators and the subjective measures.

Since the 1960s, the expression “quality of life” has been referred to in many different academic, political and ideological areas, mainly motivated by the interest of the UN, still in the 1950s, of measuring the levels of life of different worldwide communities.

In this scenario, the concept quality of life has been progressively integrating the degree of satisfaction found in family, conjugal, social and environmental life and in aesthetic existence itself. It is based on the assumption of the capacity to make a cultural synthesis of all elements that the given society considers as its standard of comfort and well-being. The term itself embraces many meanings, reflecting all the different individual and collective experiences, values and knowledge that report to it in different times, spaces and histories and as such it is a social construction marked by cultural relativity. This same relativity, which ultimately reports to the individual plan, has at least three reference axels. This first one is historical, i.e. at a given point in time of economic, social and tech-

nological development, a specific society has a given parameter of quality of life which is different for the same society at a different historical moment. The second one is cultural. Values and needs are developed and classified differently by the different societies, revealing their symbolic, cultural and ethical texture. The third aspect refers to social stratifications or classes. Researchers, while analysing societies in which inequalities and heterogeneity are very high, highlight that the standards and conceptions of well-being are also stratified: the idea of quality of life is related to the level of well-being of the upper levels of society and with the passing from one threshold to the next.

Due to the fact that quality of life is studied in different contexts and in different populations, different indicators have been used to evaluate it. In a general way, each definition reflects the context and the indicators which were studied.

In the last ten years, the definition of this concept, quality of life, has been widely discussed, without the delimitation of a single formal definition, through a diversity of studies always more and more encompassing (FLECK ET AL., 1997; SPILKER, 1996). In this way, there is recent evidence that the functional approach to quality of life should have a trans-cultural validation. Another important aspect is centred on the fact that quality of life is a transversal variable along a person's whole life (FLECK ET AL., 1997; SOUZA E GUIMARÃES, 1999; SPILKER, 1996).

Domains and dimensions of the concept

Besides the fact that quality of life has been defined, within the realm of rehabilitation, in many different ways most researchers assume that quality of life is a subjective perception of clients (BOSWELL, DAWSON & HEININGER, 1998; CHUBON, 1985; PAIN, DUNN, ANDERSON, DARRAH, E KRATOCHVIL, 1998). Based on such approach, Chubon (1985) led many studies, in which he explored the different dimensions of quality of life, for people with disabilities (lesion of the medulla, diabetes, coronary diseases, multiple sclerosis, muscular dystrophy, epilepsy and visual impairment). The results from these studies highlighted 10 different dimensions, within the following domains: work, leisure, nutrition, sleep, social support and network, income, health, love/affection, environment and self-esteem.

In a similar way, Pain et al. (1988) identified 4 domains: (1) emotional health, (2) interpersonal relations, (3) maximisation of ones potential, and (4) meaningful and gratifying project of life. In a qualitative study, Boswell et al. (1988) identified the attitudes related a persons project of life; ones work opportunities and the level of resources, as a part of the common themes obtained by people with disabilities. Additionally, the literature reveals that age, age at which the disability was acquired, educational level, social support, health, work, job and marital status correlate with quality of life for people with disabilities (MELMERT, KRAUSS, NADLER & BOYD, 1990; SCHULZ & DECKER, 1985).

Schalock (1996) identifies 8 critical components of quality of life: (1) emotional well-being, (2) interpersonal relations, (3) material well-being, (4) personal development, (5) physical well-being, (6) self determination, (7) social inclusion and (8) rights.

The Whoqol Group (1994) identifies 6 domains: (1) physical health, (2) psychological, (3) level of independence, (4) social relations, (5) environmental and (6) spirituality/religion /personal beliefs.

Complementarily, researchers stress that the concept could not be equated independently from the cultural environment where the client is integrated (KEITH, HEAL & SCHALOCK, 1996). In this way, the cognitive assessment made by each client is influenced by the system of values of the individual, while the dimensions of the values themselves are developed through socialisation. According to this assumption, researchers in the field of social psychology have identified self-regulation, social justice, gratification with ones personal project, success and protection of the environment as being part of the common transversal dimensions in the study of quality of life, independently from the type of culture (DIENNER, 1995; SCHWARTZ, 1992, 1994). However, each culture seems to generate variations in the degree of relative importance attributed to each of the dimensions of the construct.

While analysing the relevance of the application of the concept quality of life, the following conclusions have been highlighted:

- It has become a reference in the organisation of interventions, in monitoring and assessing impacts.
- It is a social construct which is influencing the development of programmes and service provision in the areas of education, training, health care and rehabilitation.
- It has been used to evaluate the levels of effectiveness and efficiency of the services provided to people with disabilities.

Operability of the concept – definition

Besides the great diversity of conceptual models proposed to delimitate the concept of quality of life, there are some consensual aspects in the literature:

- It is a measure that varies along time.
- It is an inter-subjective measure, which starts from the perception that individuals have of the different dimensions that make up life and then articulate them with the objective measures related with the satisfaction of human needs in a given social and historical context.
- Within the health context, the individual works as his own control, i.e. changes which occur in his quality of life are detected according to his own course of health, instead of an assessment of absence or presence of symptoms.
- Quality of life should be evaluated at different levels: from the assessment of

global well-being to the issues associated to the interaction of the individual with his life contexts, by crossing subjective indicators with objective indicators.

The abstract nature of the term “quality of life” explains why it takes up different meanings, for different persons, at different times and at different moments.

Considering that the construct is a social and historical product, we see many definitions appearing. Within this framework, Oleson (1990) considers that the construction of reality is inter-subjective and determined by perception and so the multiple definitions refer to the subjective judgement of each individual based on his/her own life experiences.

The theory of ecological systems of Bronfenbrenner (1989) highlights the complexity of human nature in the perspective of development, advocating those models which consider the bio-psychosocial character of the individual. In this sense, development occurs within a set of bio-psychosocial dimensions in which each subject is organised and gives sense to his/her structure of existence. In the light of complexity of the adaptive and generative systems, we may adopt a set of references of quality of life which can operate under those multiple factors. Based on such theoretical referential, the concept of quality of life emerges as a bio-psychosocial condition of well-being, integrating both the objective and subjective human experiences and the individual and social dimensions of a given social and historical moment.

Within such conceptual framework and as for the purpose of developing the theoretical model presented herein, we considered the basis of the definition of quality of life as formulated by the group of experts of the World Health Organisation (THE WHOQOL GROUP, 1995) adding the objective component of the indicators in this domain. This definition incorporates the symbolic-interactive dimension, formulating the construct as a product of the relationship of the personal system of the individual with his/her life contexts and the socio-cultural environment.

Quality of Life is the individual's perception of his/her position in life, according to the cultural context and the systems of values in which he/she lives, being the result of the interaction between his/her goals and expectations and the objective indicators available for his/her social and cultural environment.

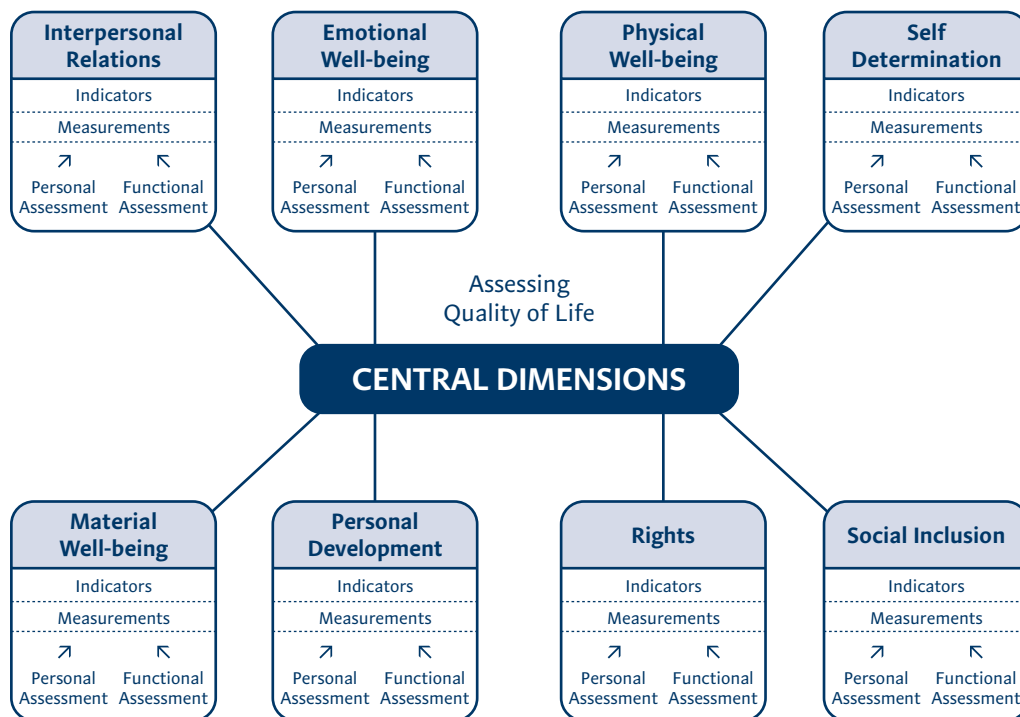
WHOQOL GROUP, 1995 – *Adapted*

Structure of the theoretical model

The development of the conceptual referential for quality of life presents a multidimensional architecture, and was founded from two main axels:

- **The Quality of Life Model** (SCHALOCK, 1996) – The author identifies 8 critical components of quality of life: (1) emotional well-being, (2) interpersonal relations, (3) material well-being, (4) personal development, (5) physical well-being, (6) self determination, (7) social inclusion, and (8) rights.

PICTURE 1. CENTRAL DIMENSIONS IN ASSESSING QUALITY OF LIFE (SCHALOCK, 1996)



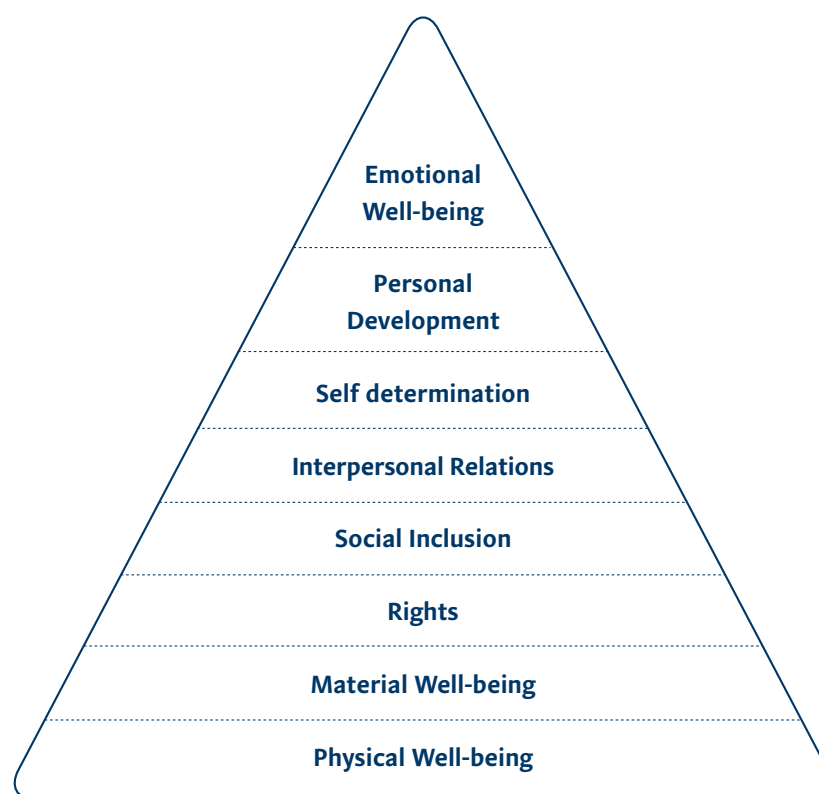
Schalock’s model presents a multidimensional and hierarchical structure.

There is a growing agreement amongst the scientific community that the concept of quality of life is not reducible to an “atomist and unitary epistemology” and so the model which was presented summarises the multiple dimensions that concur for quality of life, reflecting in a holistic and comprehensive way, the diversity of human functioning.

In the same way, Schalock’s model agrees with the literature on quality of life in three main points: first, quality of life is inter-subjective, i.e. it results from crossing subjective indicators with objective indicators; second, its central dimensions are assessed differently by different individuals; third, the value associated to each dimension varies along one’s life cycle. These three points of significant

agreement highlight the need for a concept that can be put into perspective in a hierarchical way. A model that enable's the integration of these three factors is presented in Picture 1, which is based in the works of Elorriaga, Garcia, Martinez, and Unamunzaga (2000); Flanagan (1978); Mallow (1954); and Verdugo (2000).

PICTURE 2. **HIERARCHICAL NATURE OF THE CONCEPT (SCHALOCK, 2000)**

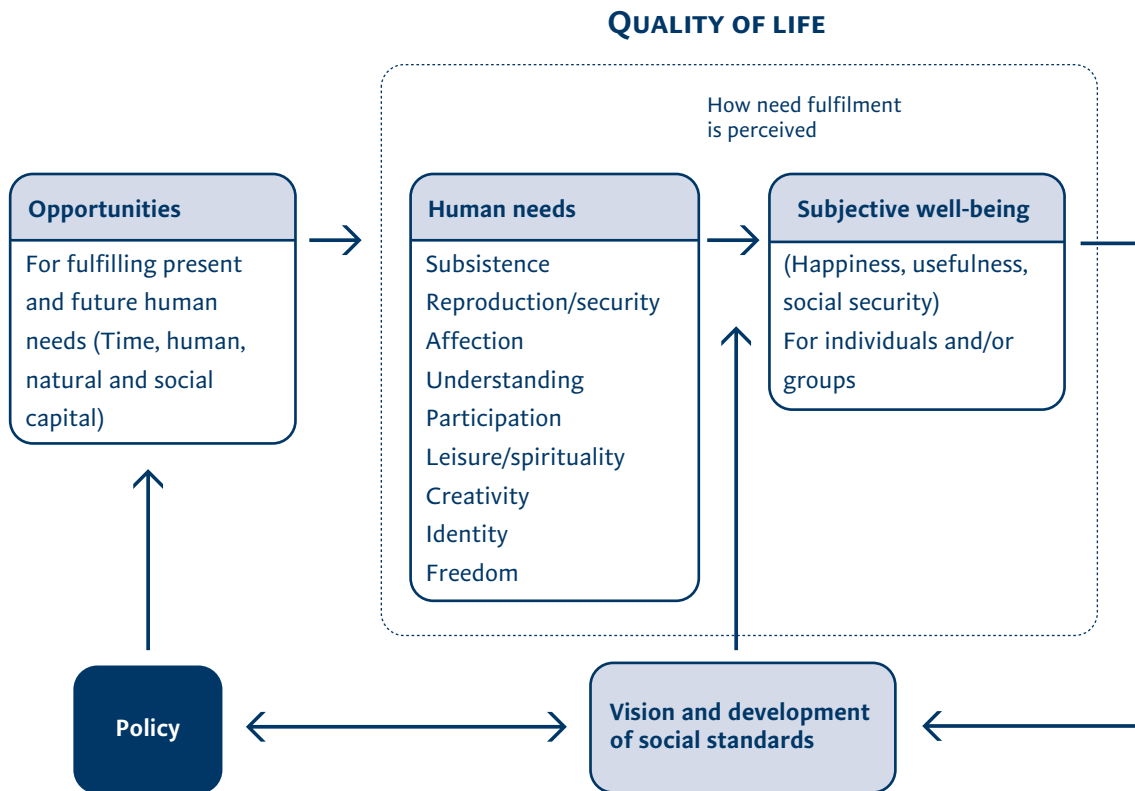


Analysing Picture 2 highlights the differentiated perception regarding the importance attributed by different individuals to the different dimensions that constitute quality of life. Different authors have suggested that the hierarchical architecture of the concept of quality of life should be taken into consideration when designing and organising interventions, as it reflects the desired functioning of people in the different domains of life.

Theory of human needs (COSTANZA ET AL., 2006) – The study developed by the interdisciplinary team of the Vermont University (Canada) generated an operational approach to the concept of quality of life in articulation with human needs, subjective well-being and the opportunities available in the environment. One of the critical points of this study is the establishment of a relationship between quality of life and the opportunities made available by the environ-

ment for the satisfaction of human needs, in order to promote human and social capital. Additionally, these dimensions are crossed with the set of policy options available for improving the structure of opportunities.

PICTURE 3. QUALITY OF LIFE AS AN INTERACTION BETWEEN HUMAN NEEDS AND THE SUBJECTIVE PERCEPTION OF THEIR FULFILMENT, AS A PROCESS MEDIATED BY THE AVAILABLE OPPORTUNITIES (COSTANZA ET AL., 2006, ADAPTED)



Based on a summary of the literature in this domain, Costanza et al. (2006) presented a structured vision of the critical domains of human needs, as expressed in Table 3:

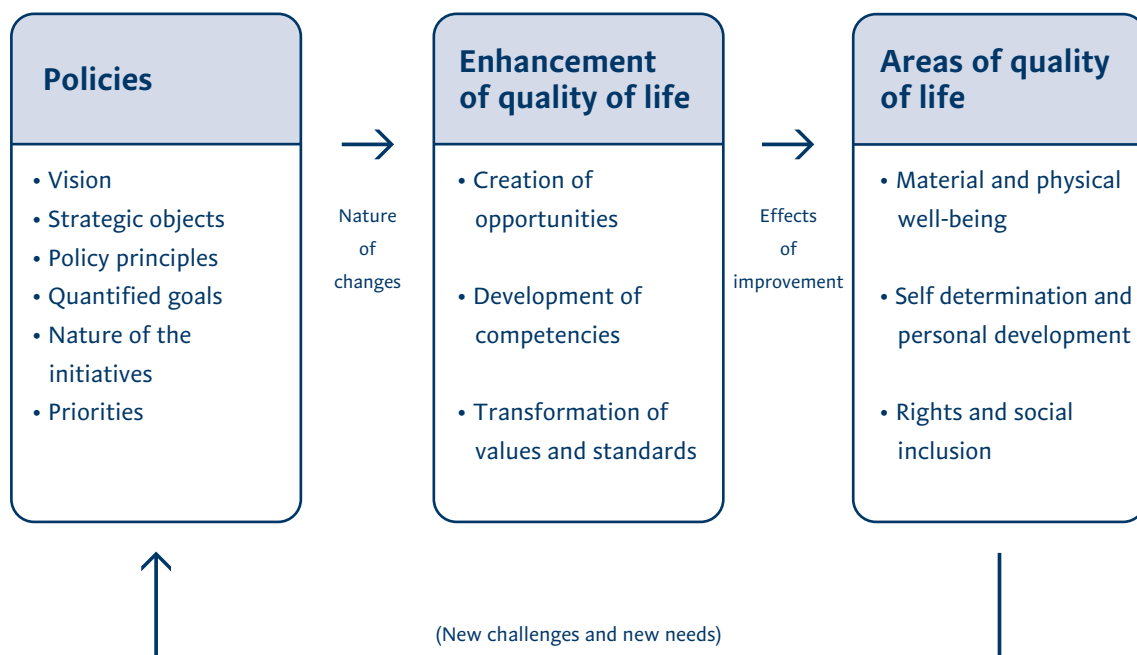
TABLE 3. SUMMARY OF THE CRITICAL DOMAINS OF HUMAN NEEDS (COSTANZA ET AL., 2006)

Human needs		
Subsistence	Reproduction	Security
Affection	Understanding	Participation
Leisure	Spirituality	Creativity/emotional expression
Identity	Freedom	

Complementarily, the study under analysis was able to highlight that the design of initiatives for the enhancement of quality of life is made up of 3 main political axels:

- Creation of opportunities;
- Development of competencies;
- Change of values and standards.

PICTURE 4. **QUALITY OF LIFE IN MODELLING REHABILITATION POLICIES**



Within such context, and based on the domains of quality of life proposed by Schalock and on the summary of human needs proposed by the team of the Vermont University, it is possible to systematise the action domains for enhancing the quality of life, as expressed in Tables 4 and 5:

TABLE 4.
OPERATIONAL MODEL STRUCTURE FOR ENHANCING THE QUALITY OF LIFE

Areas of quality of life			
	Material and physical well-being	Self determination and personal development	Rights and social inclusion
Domains of quality of life	Income and social benefits	Autonomy and resilience	Acceptance and respect
	Health care	Accessibility to communications and programmes	Legal protection
	Work and employment	Psychological development, and development of social capacities	Fulfilment of roles and functions in public life
	Housing		Solidarity
	Tourism and leisure	Ongoing education and training	Integration in social network
	Mobility	Creativity and emotional expression	Family
			Activation of rights

TABLE 5. OPERATIONAL MODEL STRUCTURE FOR ENHANCING THE QUALITY OF LIFE

Domains of Quality of Life		Strategy of Action		
		Creation of opportunities	Development of competencies	Transformation of and standards
Material and physical well-being	Income and social benefits			
	Health care			
	Work and employment			
	Housing			
	Tourism and leisure			
Self determination and personal development	Autonomy and resilience			
	Accessibility to communications and programmes			
	Psychological develop., and develop. of social capacities			
	Ongoing education and training			
	Creativity and emotional expression			
	Acceptance and respect			
Rights and social inclusion	Legal protection			
	Fulfilment of roles and functions in public life			
	Solidarity			
	Integration in social networks			
	Family			
	Activation of rights			

The model under analysis, for enhancing the quality of life, enables the foundation of two priorities in terms of policy:

- To create opportunities, which by better satisfying human needs, enable improved levels of well-being and in that way influence the subjective perception of quality of life.
- To transform values and standards so that the person's perception and the communities perception of what quality of life is, may interact in a virtuous way with the structure of opportunities.

The structure of the theoretical model which was proposed reflects the following assumptions:

- The different dimensions of impact are reciprocally related with the conditions present in the life contexts.
- The different dimensions which concur for quality of life are contingent regarding many aspects of the individual, as well as regarding different environmental dimensions.
- Physical and social environments are interdependent – the integrated interpretation of the concept of quality of life results from a multidisciplinary approach.

EVOLUTION OF CONCEPTS AND TERMINOLOGY

Historical perspective

Historically, the different approaches for intervening in the field of rehabilitation have been mostly centred on the conceptual assumptions of the medical model. However, more recently, we have seen a progressive focus on the conceptual assumptions of the social and bio-psychosocial models.

In such a historical context, social interpretations of disability are going through a transition process. This is clearly reflected in official documents related with definitions of disability and of rehabilitation. In addition to the fact that economic and demographic factors are taking up a greater and greater importance, it seems obvious that the underlying driving force for this phenomenon is based on the unprecedented politicising of disability, lead by civil society, as well as the growing demand for equality of opportunities for people with disabilities. The way the socio-political interpretation of the concept has evolved has generated advancements at the level of practices and interventions, even if with different paces of application and with obvious needs for a greater level of systematisation and structuring in the whole sector.

Consequently, some elements of the rehabilitation practices remain focused on approaches centred on the individual. Additionally, the relevance of medical interventions and of therapeutics, just have a partial impact on the context of a cultural environment organised in a privileged way for a type of life where there are no people with disabilities. In this way, the domain of public health, as well as the problems experienced by people with disabilities, become issues of political nature that can only be solved through deep structural and cultural changes, involving the systematic redistribution of resources and the development of a type of culture that values human diversity.

Classification of disability and methodologies of assessment

While in the framework of the medical model it was important to associate different impairments to different levels of disability, by mobilising criterion exclusively of medical nature, the progressive implementation of the social model in most of the European countries has brought about many challenges as to what type of categorisation better reflects the difficulties of participation experienced by persons with disabilities in their living environments. The WHO, before such a cross-way of classifications and as explained above, proposed the ICF as an operating model for characterising individual's functionality, highlighting, for the purpose of programme eligibility, the limitations of the activity and the restrictions to people's participation. In other words, while in some models one keeps assessing the individual's impairments, the ICF, coherently with the social model, emphasises that the most appropriate is not to assess changes at the level of the individual's structures or functions— even though it does not neglect them – but rather the limitations regarding the activity and the participation restrictions experienced by the subject during the interaction between his/her bio-psychological characteristics and the characteristics of the social environments in which he/she interacts. It should be noticed that this conceptual choice is not neutral, from the pragmatic point of view, as the goals for interventions become the removal of barriers and obstacles that occur within the framework of the relationship of the subject with his/her life contexts and not the interventions exclusively polarised on the individual dimension or exclusively on the societal dimension.

With the development of social policies, research has made it possible to highlight the need to identify, to define and to systematise the guiding principles that shall tend to be transversal to all sectors of social policy, as only in this way can we ensure full coherence among all different policies in the different jurisdictions. Therefore, it is relevant to discuss and clarify upon which conceptual model did the political strategy base itself, so that the set of goals, strategies, intervention processes, definition of results, allocation of resources and assessment indicators can be properly articulated and harmonised with the principles which were adopted.

Delimitation of the disability concept and making it operational

The process for making the disability concept operational had the main purposes of ensuring the criterion of: (a) international comparability, (b) analytical and legislative tradition within the Portuguese context, (c) compliance with the present conceptual referential. Therefore, a methodology based on two axels was used:

1. Analysis of the national and international referential, for operational delimitation of the concept;
2. Analysis of scenarios that may make it possible to fulfil the requirements which were defined.

In all studies which were carried out in this domain, the present difficulty for international statistical comparability was stressed, either inter or intra-sectors, regardless of the referencing organism – OECD, UN, EUROSTAT, WHO, INE [Portuguese Statistics Institute].

Consequently, a set of axels of analysis was developed, which became the structuring vectors for making the concept operational, namely:

- approach;
- focus;
- delimitation of duration and course of evolution.

Approach

As far as approach is concerned, preference was given to the adoption of the most recent guidelines proposed by the WHO, namely by explicitly adopting the bio-psychosocial model, operational through the ICF.

- The ICF has the capacity to describe human functioning in a bio-psychosocial perspective, whereas the former classification (ICIDH) focused the biomedical dimension.
- The ICF was developed at the conceptual level, in order to be applicable in different areas and jurisdictions.
- The ICF can be applied transversally to the different dimensions of culture, age, gender and is a systematic instrument for describing and measuring health and human functioning within a given context.
- The ICF is a potential instrument for social policy, for designing interventions in the areas of health, education, rehabilitation and social intervention.
- The ICF enables the description of human functioning in different domains of intervention, as well as in the environments of social participation of the individuals.

Focus

As far as focus is concerned, preference was given to the adoption of centralised data collection at the level of dimension of functionality.

- In harmony with the conceptual model proposed by the WHO, emphasising the dynamic and interactive nature (contextual/personal factors) of each person's functioning.
- Makes it possible to characterise activity limitations and restrictions for citizens' participation, identifying needs for specialised interventions in a logics of empowerment and social participation.
- Makes it possible to analyse the appropriateness and adjustment of the present policy measures, from the point of view of its objectives and of the problems detected at the level of participation of citizens along a diversified set of domains.

Delimitation of duration and course of evolution

- It seems relevant to characterise the occurrence of disabilities in terms of their consistence over time – temporary/permanent – by analysing the associated contextual factors, the consequences at the level of the activities and participation along a set of domains, in order to extract implications for social policies.
- Within the scope of the adaptability and appropriateness of policy measures to the specific needs of citizens, it is relevant to characterise disability as far as the nature of its course of development – progressive/regressive/stable. The same criterion can be applied to the dimension of pattern of manifestation – intermittent/continuous. However, and in addition to the fact that the impairment manifests itself along the life cycle of the person in a multimodal way, for delimitation and definition of the concept of persons with disabilities, the permanent nature shall be given preference. Thus, temporary manifestations of disability are excluded, as they would prejudice the analysis and the development of policies in this domain.

Considering the dimensions which were characterised and the criterion which were given preference, the following operational definition was developed:

A person with significant activity limitations and participation, in one or several domains of life, following from the interaction between the functional and structural changes of permanent nature and the surrounding contexts, resulting in prolonged difficulties of communication, learning, mobility, autonomy, interpersonal relations and social participation, leading to the mobilisation of services and resources, in order to promote the potential for bio-psychosocial functioning.

Analysis of the operationability proposed in the light of the above established criteria is explained in Table 6.

TABLE 6. ANALYSIS OF THE OPERATIONAL DIMENSIONS PROPOSED FOR DELIMITATING AND OPERATIONALISING THE CONCEPT OF DISABILITY

Operating contents	Analysis
<p><i>A person with significant limitations of activity and participation, in one or several domains of life,...</i></p>	<p>In accordance with the bio-psychosocial approach proposed by the WHO.</p> <p>.....</p> <p>In accordance with the social model.</p> <p>.....</p> <p>Places the emphasis at the level of the problems/ difficulties and obstacles which emerge from the interaction person-life contexts and, simultaneously, in the domain of the activity limitations.</p>
<p><i>... following from the interaction between the functional and structural changes of permanent nature and the surrounding contexts,...</i></p>	<p>In accordance with the bio-psychosocial approach proposed by the WHO.</p> <p>.....</p> <p>Articulates the changes of structure and function with activity limitations and participation, within the framework of the life contexts of the person.</p> <p>.....</p> <p>The permanent nature, has the purpose of establishing a greater differentiating power for the target public and to increase the operationability of the concept.</p>
<p><i>..., resulting in prolonged difficulties of communication, learning, mobility, autonomy, interpersonal relations and social participation,...</i></p>	<p>In accordance with the bio-psychosocial approach proposed by the WHO.</p> <p>.....</p> <p>Explicit presentation of the main domains, considered as critical by the literature, regarding the individual's functionality.</p>
<p><i>... leading to the mobilisation of services and resources in order to promote the potential for bio-psychosocial functioning.</i></p>	<p>In accordance with the bio-psychosocial approach proposed by the WHO.</p> <p>.....</p> <p>Articulates activity limitations and participation with the measures/strategies required for promoting the optimisation of the person-contexts.</p>

One may ask whether the delimitation of the concept as proposed above actually refers specifically to “people with disabilities” or to “people with limitations of participation”. Considering that the definition comprises a systemic approach, emphasising the interaction between a diversified set of components which generate impact upon the person’s functionality, there is no linear answer, depending on the social and historical, and social and political approach one chooses to emphasise. However, and from the conceptual point of view, preference is given to the adoption of the concept “people with disabilities” as there is total operative autonomy between the different constructs. Therefore, disability is not a linear connecting factor of the activity limitations and of the restrictions in terms of participation, but rather one of the components which, when interacting with other components, may generate impacts at the level of the individual’s functionality.

PICTURE 5. **SPECIFICITY AND SCOPE OF THE CONCEPT**



Table 7 intends to offer a systematic vision on the process of analysis of the designation which was adopted:

TABLE 7. IDENTIFICATION OF HOW MUCH THE DESIGNATION IS IN HARMONY WITH THE ASSUMPTIONS OF OUR STUDY

Designation	Advantages	Disadvantages
People with impairments	Analytical tradition within the Portuguese context.	In accordance with the medical model – focuses changes in structures and functions – focused on the person. Disarticulated from the assumptions of the social model – does not refer to the experience of impairment, as a product of the interaction between the person and the environment.
People with disabilities	In accordance with the Anglo-Saxon delimitation. Focus on the negative pole of human functioning – functioning/disability. By focusing on the experience of disability, as an interaction person environment, it refers indirectly to the mobilisation of support and resources in order to overcome and/or eliminate the obstacles to functioning in context.	Rupture with the analytical tradition in the sector.
People with functional diversity	In accordance with the social model. Focused on the management of differences, as far as their impact upon people’s participation in society.	Highly comprehensive, not allowing a relevant level of differentiation, as all citizens have diverse and different patterns of human functioning. Concept difficult to operationalise from the point of view of formulating policies and of delimitating target publics.
People with restrictions at the level of participation	In accordance with the social model. In accordance with the ICF. Places the emphasis in the problems/difficulties and obstacles that emerge in the interaction person-life contexts.	Concept with a level of delimitation far too wide and encompassing, as all events which may restrict participation occurring along ones life are included. In this way, all obstacles to participation, related with social discrimination, prejudice, stereotypes, impairment, chronic diseases, among others, are all included. Does not include activity limitations.



Designation	Advantages	Disadvantages
People with limitations in terms of activity and participation	<p>In accordance with the bio-psychosocial approach proposed by the WHO.</p> <p>Places the emphasis in the problems/difficulties and obstacles that emerge in the interaction personlife contexts and, simultaneously, in the domain of activity limitations.</p>	<p>Rupture with the analytical tradition in the sector.</p> <p>Difficult to be understood and intelligible by society in general.</p> <p>Does not include changes of structure and function.</p>
People with functional limitations	<p>In accordance with the social model.</p> <p>Places the emphasis in the different dimensions that make up functionality and human functioning.</p>	<p>Concept with a wide and encompassing level of delimitation, as all events which may restrict restrict participation occurring along ones life are included.</p>
People with disabilities*	<p>Does not introduce any rupture with the analytical tradition in the sector.</p> <p>Includes changes of structures and functions, as well as the following changes of functionality.</p> <p>Differentiates between the concepts of disability and impairment, making them autonomous, and supplying a comprehensive basis for not establishing causal relations between both concepts.</p> <p>Includes the obstacles which emerge from the interaction person-life contexts, and simultaneously, in the domain of activity limitations.</p> <p>Differentiating and delimitating power in the definition of target publics.</p> <p>In accordance with the bio-psychosocial approach proposed by the WHO.</p> <p>In strategic alignment with the Action Plan for Integrating People with Disabilities (PAIPDI)</p>	<p>Designation obtained from a compromise between the theories of the social model and of the principles of “ethics of diversity”.</p>

* T.N.: In Portuguese there is still a negative connotation associated to the Portuguese word for “disability” (“incapacidade”). Therefore, trying to achieve a balance between the legacy and the new conceptual models, it was chosen the use of the two concepts (“deficiências e incapacidades”/ “impairments and disabilities”), in order to integrate the ICF concept “disabilities”.

SUMMARY OF CONCEPTS

People with disabilities – People with significant activity limitations and participation, in one or several domains of life, following from the interaction between the functional and structural changes of permanent nature of the person and of the surrounding contexts, resulting in prolonged difficulties of communication, learning, mobility, autonomy, interpersonal relations and social participation, leading to the mobilisation of services and resources in order to promote the potential for bio-psychosocial functioning.

Body functions – Encompasses the set of physiological functions of the organic systems, including the psychological functions.

Body structures – Are characterised by the set of anatomic parts of the body making up the different systems of the individual.

Impairment – Is characterised by the existence of significant changes of structures and functions that make up the organism.

Activity – Refers to the level of execution of a task or of an action by an individual.

Activity limitations – Refers to the set of difficulties that an individual may find in the execution of activities.

Participation – Real involvement in a given situation of life.

Participation restrictions – Refers to the set of difficulties that an individual may experience in his/her involvement in real situations of his/her life, particularly when access to rights is at stake.

Contextual factors – Represent the historical narrative of individual and associated lifestyles, including two components: environmental factors and personal factors

Environmental factors – Are the physical, social and attitudinal environment in which people organise their lives.

Personal factors – Are the specific life history and lifestyle of an individual and include the individual's characteristics which are not part of a health condition.

Citizenship – Janoski (1998, adapted) defines the concept as “The individuals’ belonging to a Nation-State with certain universal passive and active rights at a given level equality”. Thus, citizenship: (a) implies a recognition of personality within a given geographical limit, which comes close to the notion of “substantive citizenship” proposed by Bottomore (1992), and which involves the recognition of a collective identity (BENHABIB, 1999); (b) includes both rights for participating in political life (active citizenship) as well as existence rights (passive citizenship) which do not depend on the subject’s competence to exercise influence; (c) refers to universal rights formally granted by law to all citizens (and not to informal and particular rights) and (d) ensures, within certain limits, equality of proceedings (for instance, in access to justice) as well as substantive.

Quality of life – The individual’s perception about his/her position in life, according to the cultural context and the systems of values in which he/she lives, as the result of the interaction between his/her objectives and expectations and the objective indicators defined for his/her social and cultural environment.

Autonomy – The capacity of the individual to define goals and to act in the direction of such resolution, mobilising resources, and individual and collective competences, managing and mediating processes, in order to achieve the desired results.

Empowerment – Process of making individual and collective competencies more complex, along which, the individuals actively influence decision making within the frame of the social environments where they are placed.

Advocacy – Mostly refers to legal or juridical activities, even though it may have a wider meaning, in the sense of initiatives of political pressure and of articulation mobilised by organisations belonging to civil society with the purpose of giving visibility to certain topics in public debate and of influencing public policies. Presently, advocacy is related to processes which generate changes in institutional systems.

Rehabilitation/habilitation – Is the mobilisation of coordinated and tailored multidisciplinary support and interventions, aiming at the resolution of emerging needs within the framework of the relationship between the person and his/her life contexts, the development of personal competencies and the mobilisation of resources in order to maximise the levels of activity and to promote participation in the community.

The differentiating element between both concepts has to do with the etiological timing of disability. In the case of congenital disability, the concept ha-

bilitation is applied, as it has to do with activating a set of measures and of complementary interventions to the mainstream services/resources since the beginning of the individual's life cycle.

In the case of an acquired disability, the concept rehabilitation is applied, as it has to do with activating specialised services in this domain, complementarily to the mainstream services and resources, in order to promote the bio-psycho-social potential of functioning.

Mainstreaming – Possibility of all people participating in the regular services, resources and structures available for the community, which process is ensured by collective empowerment to acknowledge and manage individual differences in the larger context of society.

Disability awareness – Set of strategies aiming at promoting social awareness regarding the life experiences of people with disabilities, in order to overcome attitudinal barriers and to endow the different communities with competencies for managing diversity.

Equality of opportunities – A process through which the general systems, resources, services and facilities of society – such as the physical and cultural environment, housing and transportation, social and health services, educational and working opportunities, cultural and social life – are accessible to all persons.

Integration – A process of participation of people in society, as far as they reveal and/or develop the necessary characteristics and requirements for adjusting to the general social systems and structures. Within this context, integration is defined as the set of processes of reconstruction of social order, both at the interactive level and at the systemic level.

Inclusion – A process through which society develops symbolic-operative mechanisms of transformation in order to be able to include all citizens in its general systems, and, reciprocally, creates the conditions for them to take up their roles in the different spheres of social life.

Social cohesion – Is related to the adhesion of citizens to common values in face of a sense of shared well-being, which generally includes at least three basic dimensions: one is relational (structured solidarity, social networks and social capital), another is cultural (common model of values, group identification, guaranteed social rights) and finally, another is economic connected to ensuring minimum living conditions and access to the basic pillars of insertion in the social structure – housing, education, health, employment.

Social quality – Measure of the citizens’ capacity to “participate in the economic and social life of their communities in conditions that promote their well-being and their individual potential” (BECK, MAESEN & WALKER, 1997, adapted). This concept is both promising for its multidimensionality, as well as it has the advantage of having deliberately stood out as an instrument for the assessment of social policies. This is visible in the way the four dimensions are formulated, each of them responding to a specific question:

- social and economic security, i.e. “to what extent do people actually dispose of resources along time”;
- social cohesion, i.e. “to what extent are social relations based on identities, values and standards which are actually shared”;
- social inclusion, i.e. “to what extent do people have access and are integrated in different institutions and social relations which make up ones every day live”;
- social empowerment, i.e. “to what extent are the personal capacities of individuals as well as their capacity to act, actually increased by social relations” (MAESEN, WALKER & KEISER, 2005, adapted).



Chapter 4.

**The International Classification
of Functioning, Disability and
Health as a framework for
policy design and deployment**

The appropriateness of adopting the International Classification of Functioning, Disability and Health (WHO, 2001) as an operational framework for developing a National Disability and Impairment Strategy can be supported from a range of perspectives. This chapter provides a brief review of many of these from the perspective of policy makers, people with disabilities and the general population. The approach taken is, in first place, to explore the most appropriate approach that should be adopted from an inclusive society perspective and review the ICF against these criteria.

At the heart of the Disabilities Debate is the question of “them” and “us”. This is a question that arises mainly from models of disability that create differentiations between people with and without disabilities. If one evaluates both the medical and social models from this perspective it becomes apparent that both approaches require the division of the population into disabled and non-disabled groups. However, if one takes the broad view of disability it is not difficult to conclude that most people in society will experience disability at some time in their lives. It is also clear that very many people are currently in the process of becoming experiencing a disability at any given time. Thus the debate in favour of characterising disability as a dynamic continuum rather than a set of discrete and stable states is extremely strong.

Many arguments have been made against the adoption of a dynamic interactive model of disability as the basis for disability policy but most of them are either based on issues of feasibility and practicality or evolve from the institutionalised perspectives and positions of vested interests in the field. One of the main factors inhibiting the adoption of the approach to policy development and implementation is that most administrative, funding and regulatory mechanisms are predicated on a dichotomous model of disability. This partly because it is essential to allocate the scarce resources in the disability sector to those who are most in need and partly occurs because it is convenient for those responsible for operating the system, i.e. politicians, administrators, services providers and regulatory agencies.

The debate revolves around the dilemma facing Society and the State about who is “eligible” for “what”. Previous approaches to resolving this dilemma have attempted to base eligibility indicators upon the notion of disability as a stable and relatively permanent state or condition. But what emerges when examining these supposedly objective definitions of disability is that they differ not merely between Member-States or jurisdictions but that even within the same jurisdiction the definitions of disability differ depending on the intention of the statutory instrument in relation to resources and objectives. For example, eligibility for social security payments and long term disabilities payment tend to be far more stringent than eligibility for access to rehabilitation or social inclusion programmes. Both of these often differ from the definition used in anti-dis-

crimination legislation. In fact, what is clear is that competent authorities have implicitly accepted that disabilities exist along a continuum from mild to more severe and has reflected this in setting out the socio-political criteria for eligibility for programmes and funding.

Once the link between questions of eligibility and the meaning of have been severed, there are very few arguments in favour of adopting a dichotomous model of disabilities as basis for policy forming and implementation. Further, once the decision has been made to accept that disabilities occur across a dynamic continuum, there is effectively only one coherent framework that can be used to capture and characterise this from a policy and practical standpoint, i.e. the ICF.

The ICF offers a useful hybrid description of disabilities that can be used by policy makers, researchers, people with disabilities, providers and administrators to come to a common understanding of the meaning of disabilities and which respond to many of the criticisms of both medical and social models. It also provides a comprehensive framework for operationalising that description.

In the words of Rachel Hurst (2001), an international disability activist from the UK, who participated in the development of the ICF:

.....
“The ICF, if properly used, supports the rights model of disabilities and will help us collect the evidence to show what our lives are really like. It also officially states that impairment arises from the impact of environmental factors on disability and functioning.”
.....

The ICF can be used to develop a matrix of measurable indicators of sustainable development and a society based on celebrating difference and ensuring rights for all, a society where people with disabilities rights are underpinned and human dignity respected. A society which could be helped by the ICF – then why not work towards this vision?

The ICF is a classification that allows a comprehensive and detailed description of a person’s experience of disability, including the environmental barriers and facilitators that have an impact on a person’s functioning. The recognition of the central role played by environmental factors has changed the *locus* of the problem and hence, the focus of intervention, from the individual to the environment in which the individual lives.

Disabilities are no longer understood as a feature of the individual, but rather as the outcome of an interaction of the person with a health condition and the environmental factors. The adoption of the interactive model and the impacts of environmental factors in all aspects of health and functioning that are explicit in the ICF is a step forward (SCHNEIDERT ET AL., 2003).

The proper use of the environmental factors within the ICF will ensure ap-

appropriate policies, systems and services provide measurable indicators for health status and sustainable development and underpin the recognition that disabilities are a human rights issue (HURST, 2003).

Thus the ICF has a number of features which make it useful at the policy level. It has the capacity to incorporate both medical and social aspects of the disabilities phenomenon. It is a robust, coherent and systematic classification that can be used for describing and documenting the complexities of the disabilities phenomenon. Additionally, there are a number of other useful characteristics which make it an ideal instrument for designing and deploying disabilities policies within a jurisdiction.

KEY CHARACTERISTICS OF THE ICF FROM A POLICY PERSPECTIVE

Levels of application

The ICF can be applied at an individual, institutional or societal level. It is capable of being applied in the case of a person experiencing a reduction in functioning as a result of a health condition to document that person's life experience, to specify appropriate interventions and to set target outcomes. Further, it provides a common language to facilitate communication between professionals (STUCKI ET AL., 2002).

At the institutional level, it has the potential to describe the strategic objectives of an organisation operating within the field of disabilities, to contribute to the development of more holistic and relevant programmes, to structure research agendas, to contribute to the continuing professional development of staff and to provide the basis for quality standards and outcome evaluation (RI – EUROPE LANDMARK STUDY, 2005).

At a societal level, the ICF can be used to evaluate the current disabilities response within a jurisdiction, to identify where statutory and regulatory mechanisms are acting as barriers to full participation for people with disabilities and to provide a framework for the design of more inclusive and responsive policies (MHADIE, 2005). The ICF has been particularly useful in the design of statistical studies to document the lived experience of people with disabilities and has been successfully used in adapting questions in a population census to reveal the distinction between impairment and participation. It has also been used in national disabilities studies to document the impact of existing policies (STATISTICS CANADA, 2006). Thus, adopting the ICF as a framework for policy development means that the deployment of such policies can be systematically

mapped at the institutional and individual levels. As a result, the evaluation of the impact of disability policies becomes easier (e.g., NORTHERN IRELAND STATISTICS & RESEARCH AGENCY, 2007).

Relevance domains

It is acknowledged that disabilities are a matter of concern across many policy domains. It is also accepted that a major disabling factor in society is the fragmentation of responses within and between different domains of policy. The desirable response to disabilities is one that is “joined up” across policy domains. One major challenge in achieving cross-cutting disabilities policies is that the language and definitions of disabilities differ from one domain to another. For example, the way in which disabilities are usually described within the domain of health differs qualitatively from descriptions used in education, training or equality.

Each domain specifies its disabilities response either in legislation or through regulatory mechanisms. What is required is a way of conceptualising disabilities across policy domains guaranteeing the coherence of the diversity of criterion for eligibility in each domain. The ICF provides a framework which can be applied within the domains of health, education and training, work and employment, social affairs, social inclusion, transport, communications, environment, justice and equality (e.g., COMMITTEE ON DISABILITY IN AMERICA, 2007; WYNNE & McANANEY, 2004). It does not require the unification or standardisation of criterion or strategies while at the same time each policy response can be mapped on the multidimensional axes of the ICF (e.g., NATIONAL COMMISSION ON DISABILITY, 2005).

Specificity of description

One of the fundamental strengths of the ICF is that it remains coherent at all levels of description. At the most general level, the ICF specifies the inter-relationships between health condition, functioning, activity limitation and participation restriction in the context of the intervening variables *environmental* and *personal factors* (SCHNEIDERT ET AL., 2003). At a policy level the environmental chapter specifies the range of policies, systems and services that are implicated in the disabling or enabling process within a jurisdiction. It can be used to characterise the impact of mediating mechanisms and systems of provision upon the lives of citizens with disabilities (e.g., BRICK-NELL & MADDEN, 2002). In combination with the International Classification of Disease (ICD) 10, it can be used to provide a holistic description of the needs and strengths of an individual

(McDOUGALL & MILLER, 2003). The consistency with which the ICF describes disabilities from the general to the specific makes it an ideal tool for tracking the impact of policies on individuals.

Sensitivity to intervening factors

An important characteristic of the ICF from the perspective of policy development is that at least at the framework level, it acknowledges that disabilities will impact differently upon people depending on a range of other factors. Thus, the meaning of disabilities for someone who is fifty-five years of age is very different to the experience of a person who is twenty-five years of age. It is also the case that disabilities can impact differently upon men as opposed to women. Disabilities are viewed differently in different cultures and can be experienced differently depending on a person's ethnic origin. Disabilities will have different implications depending on a person's level of income and level of education. While the ICF acknowledges the importance of personal factors in the disability process, it stops short of documenting these within the classification. This is appropriate given that its primary function is to provide a systematic way of describing health, functioning and disabilities. Nevertheless, from a policy perspective acknowledging the importance of personal factors and demographics in the disability process can guard against "one size fits all" approaches to disabilities policies (OCDE DISSEMINATION CONFERENCE, 2003). The interaction between impairments and other factors such as social status and economic status can also be useful in specifying eligibility criteria for certain supports, programmes and interventions.

Scope of activity

The ICF has been used at policy, research and individual levels in many jurisdictions to date. From a policy perspective it is regularly applied in the assessment of population health, in monitoring the impact of disabilities in both economic and social terms and in providing an evidence base for policy makers in relation to a range of policy interventions across the domains of health, social security, work and employment and education.

In particular the ICF highlights the importance of not simply documenting epidemiology but also evaluating the responsiveness of systems of provision, efficiency of delivery and the effectiveness of performance. Within the field of research the ICF is being considered in areas as diverse as public health, (CLANCY & ANDRESEN, 2002), social inclusion (WYNNE & MCANANEY, 2004), work and employment (BEATON &

MUSTARD, 2003), equality (HURST, 2003) and social security. It is particularly useful in describing interactions between factors in the disability process, examining the complex relationships between structural and agency explanations of outcomes, facilitating multi-disciplinary research and evaluation programmes.

The ICF enhances the explanatory power of research particularly in relation to service utilisation, needs and outcomes and costs and impact. Within the field of health the ICF has broadened out the focus beyond that of impairment, has mainstreamed the concept of disability to the general population, has provided common domains of description which are independent of diagnosis, helped to link data from both health and disability sources and emphasised the importance of environmental factors in planning supports and interventions.

At the level of clinical practice the ICF provides a structure for carrying out needs assessment, planning interventions and supports and monitoring outcomes and progresses. The use of specific core sets (WEIGL ET AL., 2004) for different conditions provides a systematic and consistent approach which can be applied across policy domains, services and in different regions.

The ICF can also be useful in managing systems of provision in that it is ideally suited to the construction of electronic records, monitoring service performance, measuring consumer satisfaction, comparing the impact of different interventions and mapping utilisation patterns.

Early intervention and prevention

One key contribution that the ICF makes to the disability policy is based on the emphasis of the necessity of developing policies, systems and services to prevent impairments. Thus the ICF bridges the gap between current disability policies and public health policies. In fact, the ICF provides a coherent and systematic approach to the challenge of mainstreaming. Specifically, from an ICF perspective mainstream and specialised policies and services must be considered along a continuum which is matched to the capacity and needs of the individual student.

For example, within education and training provision the application of the ICF to the allocation of resources would require a multi-faceted approach in which funding is applied to both mainstream institutions and to individuals with specific needs. The allocation of resources would be based on three different types of interventions:

- An allocation to each school and training centre to respond to participants who are experiencing difficulties but who do not require diagnosis and to adapt infrastructure to create a more inclusive environment. These funds could be allocated on the basis of statistical estimates of the number of people within the population likely to experience difficulties.

- Further funding could be allocated to a training centre or school based on the number of participants in the institution with documented impairments or disabilities. Once again, funding would be provided to the school rather than linked to the individual but ring-fenced for the creation of more inclusive environments and the provision of learning supports.
- In addition to these two funding allocations, a provision should be available to allocate resources to an individual on the basis of an individual assessment of needs where mainstream resources have proved insufficient over time to prevent a development of moderate participation restriction.

Alongside this phased and targeted approach to resource allocation within the mainstream education and training systems, public health and social security resources can also be balanced between prevention, early identification and early intervention services which are focused upon the general population and specialised accommodations and supports which are targeted at people experiencing disadvantage as a result of a disability.

ASSESSING DISABILITY AND ALLOCATING RESOURCES

The appropriateness and suitability of the ICF as a frame for assessing disabilities and eligibility for supports and services needs to be judged in broad terms and particularly in terms of whether a bio-psychosocial approach be adopted to assessing disability and planning interventions.

Minority and deficit approaches to determining disabilities

Historically, there have been two other approaches adopted. The first of these is the medical/classificatory approach in which systems of provision for people with disabilities operate on the basis of disabilities categories or diagnosis. This approach has many advantages including administrative convenience and simplicity in operational and financial systems. The approach is based on the premise that the diagnostic category to which a person has been designated can be used as the key to the type and level of education required (TRIANO, 2000).

This approach is most often in evidence in systems where distinctions are made between different types of disabilities in funding and developing services. It is also associated most strongly with a specialised/segregated approach to delivery. There are a number of sub-optimal consequences of the application of this approach:

- One characteristic of this approach is that a person needs to attract a medical diagnosis in order to be eligible for services.
- A second characteristic is that services are developed for people within a narrow band of eligibility.
- A third characteristic is that organisations that deliver services define themselves in terms to specific diagnoses, i.e. general learning disability, autism, cerebral paralysis etc. A corollary of this is that when the statutory authorities are allocating funds they do on the basis of disability categories, i.e. physical, sensory, learning disabilities and the resources go directly to the service providers rather than to the person or the family.
- A fourth characteristic is that services are designed not so much around the needs of the individual but rather around the stereotyped requirements of a particular diagnostic category.

The implications of these types of approaches for the person, his or her family and professionals working in the field are substantial:

- The system dichotomises people into those who are in the diagnostic field and those who are not. This means that someone with borderline eligibility is denied resources until his or her condition deteriorates sufficiently to meet the criteria.
- Those who are assessed as eligible are assigned a diagnostic label which brings into play the negative consequences of stigma associated with disabilities.
- People with a double diagnosis find it very difficult to get appropriate services as they fall between “two stools”.
- People with disabilities and the parents of children with disabilities are forced to seek a diagnosis in order to get services.
- Psychologists and other allied health professionals end up acting as “gatekeepers” of resources as assessments focus on eligibility rather than upon needs and strengths.
- The approach tends to support and to proliferate stereotypes of disabilities rather than treating each learner as an individual.

The inclusive society approach to disability

An alternative view of disabilities places it in the external environment and highlights the role that attitudes, systems and services (or the lack of them) play in its creation. The main argument for this view of disabilities is that if we treat people differently and educate them in a parallel system, they will develop differently and never fully integrate into the mainstream of society and society will always view them as different and stigmatised.

This approach places responsibility for the creation of disabilities on the very

institutions originally set up to give them answers. For example, placing a young learner in a segregated educational environment ultimately means that he or she will not learn to assimilate into the mainstream, will acquire a label and a stigma, while at the same time the resources required to achieve mainstreaming are “locked up” in the specialised segregated system. From this perspective, it is those who assign a diagnosis that create disability.

From this standpoint the role of disability services needs to be radically changed and its primary goal refocused on creating mainstream educational, social, work and community environments in which individual differences arising from a health condition or functional impairment do not disadvantage any citizen. The approach emphasises the equality of outcomes, full participation in mainstream services and contexts, independence and reasonable accommodation. The implications of this approach to disabilities is that resources need to be targeted at changing how disability is dealt with in the mainstream through training mainstream professionals and adapting buildings and challenging attitudes rather than maintaining the specialised system which is seen as the origin of much of the isolation and exclusion experienced by people with developmental disabilities.

This can be most clearly seen in the inclusive education approach (EDUCATION – INCLUSIVE EDUCATION & SPECIAL EDUCATIONAL LINKS), which requires education systems to change and respond to the learner with special educational needs rather than expecting the learners to adapt to the education system. However, there is significant concern that the concept of inclusive education will be used to disestablish the special education sector without properly resourcing the mainstream.

The inclusive education movement has developed over the past 15 years in parallel with the dissemination of the social model of disability to the point where the underpinning concepts and principles have been generally accepted in most developed economies. The dilemma is no longer about whether a deficit or an inclusive approach is the right choice for special education but how it is possible to move from a position where most systems are now deficit based to where they need to be in order to meet the ideals of the inclusive society aspiration.

Determining eligibility and documenting needs

One key issue in this evolution is how the limited resources available to disabilities services can be targeted effectively at those who most need supports and interventions. Within a system structured on the basis of the deficit model, eligibility for resources is based on a recognised diagnosis and professionals act as “gatekeepers” to resources by ensuring that all those who are given access to resources meet the eligibility criteria.

It is more problematic within a system based on an inclusive community model.

Firstly, resources need to be targeted at adapting the mainstream system rather than at individuals with disabilities. Secondly, the inclusive approach is anathema to labelling learners and so it is necessary to construct an alternative means of delivering social services to those who need them most. However, in most jurisdictions, competent authorities still allocate budgets on the basis of disability categories/labels. Thirdly, the limited resources available within the system for disability initiatives and programmes would be completely absorbed if they were all allocated to making mainstream infrastructure accessible and this would only address the needs of that minority of people with mobility disabilities.

One mechanism that has been used in a number of jurisdictions for allocating and coordinating services is Individual Planning or Person Centred Planning. (MANSELL & BEADLE-BROWN, 2004; DUFFY & SANDERSON, 2004). In this regard the Individual Educational Plan (IEP) is probably one of the best developed. This operates on basis of a Statement of Need rather than on a diagnostic label alone to allocate resources. Thus, someone with general learning disabilities is provided with a Statement of Need which specifies the support and interventions required (either mainstream or specialised as appropriate) and on this basis an IEP is developed through a multi-disciplinary process which responds to the educational, social and health care needs of the individual. It is important that the statement of need has a statutory basis so that any resource specified in the statement has a legal mandate to be provided. One critical aspect of such a system is that the statutory body responsible for identifying needs is independent of the authority responsible for providing the resources.

The Statement and IEP system can operate alongside the development of the mainstream system through the adaptation of infrastructure and the training and continuous professional development of mainstream actors and professionals.

The need for a bio-psychosocial approach to documenting disabilities in society

The effective operation of a system based on individual assessment of needs and individual planning depends on the adoption of an appropriate model of disability. If the systems are based on a deficit model then the assessment of needs will focus solely on the functional limitations of the person and the only needs included in the statement will refer to interventions for building the capacity of the individual. If the system is based on a more social model, the focus will be on changes to the environment and the provision of supports to assist the learner in the mainstream setting. Either of these approaches will result in an unbalanced individual plan. It is essential that both functional and activity limitations and environmental barriers are addressed in the statement of needs and hence in the individual plan.

In order to carry out a comprehensive assessment of need it is essential that

it be based on a holistic model of human development. In effect, such a model is at the core of the bio-psychosocial conception of human development. The application of the bio-psychosocial model to document profiles of functioning and disabilities of people is strongly recommended by many international experts in the use of the ICF (SIMEONSSON ET AL., 2003; AMERICAN SPEECH – LANGUAGE – HEARING ASSOCIATION, 2004).

THE ICF AS A FRAMEWORK FOR DOCUMENTING INDIVIDUAL NEEDS

Once the argument in favour of a bio-psychosocial approach to the development of a national disabilities strategy has been accepted, the remaining issue is which conceptual framework best reflects the principles and values of the bio-psychosocial model and can provide a systematic means of documenting and responding to both individual and environmental needs and strengths. From this perspective there is no framework more appropriate and relevant than the ICF.

The ICF possesses a number of characteristics that make it an ideal framework to support the development and implementation of a comprehensive assessment of needs process (WHO, 2002):

- The ICF construes Disability as “*a dynamic interaction between the person and contextual factors*” as opposed to the static dichotomous characterisations inherent in the deficit and social models. In this regard it is ideal as a basis for identifying individual needs and strengths and the barriers and facilitators the person’s environment.
- The ICF is an integral part of a system of classification that includes the International Classification of Disease. Therefore the primary and secondary diagnoses can easily be incorporated into the assessment using a combination of ICF and ICD 10.
- The ICF provides a systematic way of documenting not only an individual’s functional capacity but also his or her limitations in carrying out activities. This is crucial given that people with the same functional impairments can differ significantly in the extent they can deal with day to day life activities such as self care or communicating.
- The ICF provides an equally systematic means of documenting the extent to which an individual’s environment is assisting him or her to perform above or below her capacity. For example, the ICF allows an assessment team to document the case where a learner is communicating more effectively as a result of an assistive device than would have been possible given his or her level of functioning. Similarly, the ICF allows a team to specify the extent to

which the attitudes of a person's family are acting as a facilitator or a barrier to participation in mainstream education.

- The language of the ICF is neutral unlike the terminology associated with many deficit based classification systems. In this regard it is more acceptable to parents and learners and easier to understand by teachers.
- The qualifier system of the ICF allows an assessment team not simply to specify the degree of strengths, needs, barriers and facilitators but also to indicate those which are amenable to change either by the provision of capacity building interventions, providing supports or by changing the environment.
- The ICF reflects a number of other important characteristics which make it an ideal framework for reviewing and assessing individual needs and strengths.
 - › The ICF has been designed so that it can be used to systematically describe **human functioning** in general and not merely **disability**.
 - › It is based on a *universal* model of functioning and activity and rather than a **minority** model.
 - › It is **integrative** in that it incorporates not merely medical aspects but also psychological and social elements of the disability process.
 - › It describes an **interactive** process in which the relationship between function, activity and participation are not linear progressive but are amenable to change.
 - › It incorporates the concept of **parity** in that a functional impairment that arises from an accident or developmental process is treated the same regardless of etiological causality.
 - › It is **context – inclusive** and does not attribute impairment or disability to the person alone.
 - › It has applicability in a **culturally diverse** society because the concepts which it incorporates are not particularly based on western ideology.
 - › It is designed as an **operational** tool for policy development, research and clinical applications it is not simply theory driven.
 - › It is designed to be relevant to the **life span**. It is not solely adult driven and thus can be used to capture developmental differences.

One of the primary aims of the ICF is to provide a scientific basis for the consequences of health conditions. One of the well documented consequences of having a health condition as a child is that it very often disrupts participation in education. The ICF has the flexibility and power to document the educational consequences of a health condition in terms that are highly amenable to planning adequate solutions, support and compensatory interventions.

The development of the ICF Children and Youth version

One of the main drawbacks to the widespread application of the ICF in the field of special education has been the lack of a child version of the framework. This was particularly problematic because the adult version could not cater for the differences in the nature and type of functioning of children compared to adults. It is not acceptable to conceptualise a child as a smaller version of an adult. Children are in a constant process of flux, change and progressions through development. In fact in most standard based assessment tools for children it is necessary to produce separate norms for every six months of age such as reading, IQ, etc. It is also the case that children and adolescents are very often and appropriately restricted by their environments in their participation in many major life activities such as drinking alcohol or gaining admission to nightclubs. The types of participation and environments are very different for younger people.

These differences were well recognised by the WHO which requested in 2002 that the ICF be adapted for universal use in health, education and social sectors for children and youth. As result a working group carried out the work between 2002 and 2004 and field trials took place in 2005 and 2006. The applicability of the ICF-CY (LOLLAR & SIMEONSSON, 2005) was examined using four age-group questionnaires; infancy (0-2), early childhood (3-6), middle childhood (7-12) and adolescence (13-18). As a result the ICF version for children and youth (ICF-CY) was published by WHO this year. The ICF-CY is intended to facilitate continuity in documenting functioning, activity, participation and the role of the environment across the transitions that human beings make from childhood to adulthood and to facilitate communication between professionals and service providers and parents.

The ICF-CY has the potential to overcome some of the challenges currently facing assessment and intervention in special education. Firstly, given its structure it can highlight functional differences between children with the same diagnosis. Secondly, it can emphasise functional similarities between children with different diagnoses. Thirdly, it can bridge the gap between assessment and intervention. Fourthly, it can be used to document changes as a result of interventions not only in the performance of the child but also in the child's environment.

The main modifications to the adult version of the ICF were (IBRAGIMOVA ET AL., 2005):

- Modifying or expanding descriptions of existing codes.
- Assigning new content to unused codes.
- Modifying inclusion and exclusion criteria of existing codes.
- Expanding the qualifier system to include developmental aspects.

Basically, the ICF-CY is consistent with the organisation and structure of the adult version, expanded to cover the essential aspects of functioning and en-

vironment of childhood and adolescence. Some 237 changes have been made to ICF codes particularly in the area of activities and participation. For example, code d1200 – touching, smelling, tasting captures a particular development stage as do the codes d1330-d1332 which cover acquiring single words or meaningful sounds, combining words into phrases and acquiring syntax (LOLLAR, S.D.).

A manual has been developed by the National Institute of Special Needs Education in Japan for the use of the ICF-CY which has been approved by the WHO.

The ICF is now widely used internationally in a number of policy fields including health, social care, employment, social security and education. The clinical application of the ICF in terms of assessing needs, evaluating progress and planning interventions has been well accepted in most sectors at this point in time. The research applications of the ICF in terms of measuring outcomes and the impact of environmental factors on activity limitations and societal participation have been widely acclaimed. It has been used in social policy development to plan social security systems and redesign disabilities legislation and policies. It is also widely used statistically to collect and report data in population surveys or in administrative databases for managing systems of provision. With the publication of the ICF-CY it has lifespan relevance and can be used within education as a framework for assessing functioning and activity, monitoring progress and planning interventions.

The ICF can be recommended as a policy framework from two perspectives. On the one hand, incorporating the ICF into the conceptual and strategic framework of a National Disability Strategy can help to avoid some of the limitations associated with a number of previous approaches to disability policy which have been limited in scope, ambiguous in focus, fragmented in implementation, difficult to disseminate and impossible to monitor in terms of impact. On the other hand, it provides an integrated and coherent approach to the policy which is capable of capturing the dynamic and complex nature of disabilities, characterising its social construction, balancing specialised and mainstream initiatives and programmes, specifying cross-cutting and "joined up" responses, supporting early intervention, setting measurable targets and measuring its impact in terms of the lived experience of citizens with disabilities and their families and carers.



Chapter 5.
**People with disabilities
in Portugal**

The present study includes a national survey which was carried out in two stages. The first stage was a questionnaire to a representative sample of the population residing in Mainland Portugal, aged between 18 and 70 years, with the purpose of collecting data for characterising people with disabilities in the Portuguese society ⁽⁰²⁾. At a second stage, a different questionnaire was given to the population with disabilities which had been identified during the first stage, with the purpose of analysing the correlation between the rehabilitation system and the courses of life of this population ⁽⁰³⁾.

In this chapter, we present some of the global results which were obtained for achieving the above mentioned purposes.

One of the most important basic information from this study is that population with disabilities represents 8,2% of the surveyed universe. This figure was calculated from the operationalisation of the concept of disability, as defined in the former chapter.

CHARACTERISING ELEMENTS

In order to characterise people with disabilities (PWD) it is important to record the elements that enable us to have a clear representation both of their social profile, as well as of their cultural profile, comparing that image, as much as possible, with that of the general Portuguese population, and then complementing these elements with data on the weight of the different types of disabilities which were recorded ⁽⁰⁴⁾.

(02) *The size of the sample is of 15005 individuals, being representative, with a confidence interval of 95,5%, and with a margin of error of 0,8, stratified by NUTS III, with random selection as far as the place of residence of the respondent. More detailed information on the methodological strategy and techniques which were adopted in the survey are available in the following publication “Elementos de caracterização das pessoas com deficiências e incapacidades em Portugal” [“Characterising elements of people with disabilities in Portugal”].*

(03) *This sample is made of 1235 persons, selected from the sample of the first stage, according to the above defined concept of person with disabilities – person experiencing significant impairment which is not solved with the use of assistive products, to which is associated one or more permanent changes in the body functions.*

(04) *The detailed analysis of the survey’s results may be consulted in the following publications “Elementos de caracterização das pessoas com deficiências e incapacidades em Portugal” [“Characterising elements of people with disabilities in Portugal”] and, “O sistema de reabilitação e as trajetórias de vida das pessoas com deficiências e incapacidades em Portugal” – [“The rehabilitation system and the life pathways of people with disabilities in Portugal”]. The data from the survey does not always enable a direct comparison with the national population, and so, in that case, only the results on the population with disabilities are presented.*

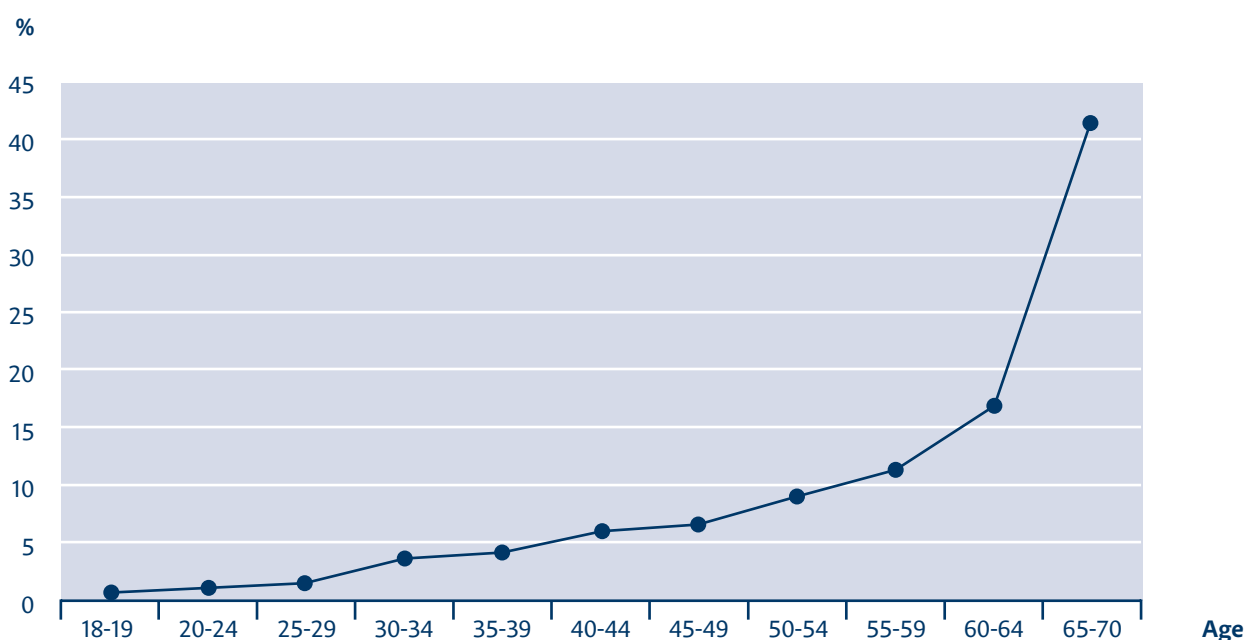
TABLE 8. GENDER AND AGE (%)

		PWD (%)	Population of Mainland Portugal (%)
Gender	Females	67,9	51,8
	Males	32,1	48,2
Age	18 – 24 years	1,2	11,8
	25 – 49 years	20,2	48,6
	50 – 64 years	37,6	26,1
	65 – 70 years	41,0	13,5

The first relevant indicator is the significance of females in percentage terms (Table 8). With 68% of women and 32% of men, the group of people with disabilities presents a significantly higher rate of women than in the general population in Mainland Portugal.

In terms of distribution by age groups, we also found some very expressive results. The percentage of people with disabilities grows in a significant way as we move from the younger ones to the elderly, reaching its peak in the age group from 65 to 70 years (41%), as we can see in Graph 1. This population is also clearly older (in average 58 years of age) than the general population in Mainland Portugal (44 years). As we can see in Table 8, the two populations have significantly different distributions by age groups.

GRAPH 1. PERSONS WITH DISABILITY BY AGE GROUPS



As far as the correlation between gender and age in people with disabilities, it follows the same pattern of the general Portuguese population: the proportional weight of women is greater than that of men at the most advanced ages.

Thus, the population with disabilities is characterised, (according to these two variables) by an overrepresentation of the elderly and of women, comparing to the national Portuguese population.

TABLE 9. **MARITAL STATUS (%)**

	PWD (%)	Population of Mainland Portugal (%)
Single	11,2	21,4
Formely married	61,9	59,9
Not formely married	2,2	4,8
Separated/divorced	5,3	6,2
Widow/widower	19,5	7,8

As far as marital status, there are no significant differences between the population with disabilities and the general population, nevertheless they do exist. In both cases, the formerly married population is predominant (62 and 60%, respectively), and this figure is even slightly higher among PWD. This data reveals that the population with disabilities does not stand out from the standard at this point.

The greater proportion of widowers and the smaller percentage of singles are certainly due to the fact that this population is elderly and that there are more women, who marry for the second time, less often than men, and that have a greater life expectancy than men.

The greater proportional weight of widowers, and the smaller percentages of divorced and of non-formerly married (to which add the greater weight of formerly married) suggest that this population has greater difficulties in marrying again after the death of the spouse and live conjugal relationships which show a greater investment in formalisation and in security.

The greater proportion of widowers and the smaller percentage of singles can also be due to the fact that this population is comparatively elder and that there are more women, who marry for the second time, less often than men, and that have a greater life expectancy than men.

The specificities of respondents with disabilities emerge once again in terms of level of education. About 21% of those aged between 25 and 70 years did not complete the 1st level of basic education (in the Portuguese population in general the rate is just 4%), those that studied more than basic education are only 5% (against 25% for the whole country) and those with average or higher education are only 2% (whereas the national percentage is 9%).

TABLE 10. LEVEL OF EDUCATION (25-70 YEARS)

	PWD (%)	Population of Mainland Portugal (%)
Does not know how to read or to write, or did not attend to school	21,1	3,6
1 st level of basic education	57,2	36,3
2 nd level of basic education	10,6	16,4
3 rd level of basic education	6,1	18,9
Secondary education	3,2	15,6
Medium/higher education	1,7	9,3

We can also see that the illiteracy rate of respondents with disabilities is nine times greater than for the population of Mainland Portugal.

In Portugal the level of education among elderly women is lower than that of men; therefore there is a global influence of age and gender in this unbalance. However, it can be seen that people with disabilities have lower levels of education than the general Portuguese population for all age levels, which implies that there is a specific discrimination.

The population with disabilities has academic qualifications characteristically lower than the national average. To this specificity in terms of the level of education, is associated a similar pattern of engagement in the labour market.

In Table 11 it can be seen that the figure for the rate of activity among people with disabilities (aged between 18 and 65 years) is less than half the figure of the universe of reference ⁽⁰⁵⁾. To this adds a rate of unemployment two and a half times greater, and an employment rate lower than half of the country rate.

TABLE 11. RELATIONSHIP WITH LABOUR

	Population of Mainland Portugal (%) (18 – 65 years)	PWD (18 – 65 years)	PWD (18 – 35 years)
Rate of activity	100	49	74
Rate of unemployment	100	246	217
Rate of employment	100	40	64

⁽⁰⁵⁾ The figures in the table represent ratios which have as a reference the population of Mainland Portugal, aged between 18 and 65 years (which, thus, take up the value 100).

Even in the younger generations (aged between 18 and 35 years) an unfavourable condition remains when comparing with the national average, even though in a less significant level.

These data configure a situation of noticeable exclusion of people with disabilities in the labour world.

To the respondents with disabilities with a job (or that have ever worked) it was asked that they mention which is the present/last occupation and professional situation, and from that information their socio-professional category (SPC) was then calculated.

Table 12 shows the distribution by socio-professional category of the respondents with disabilities, as well as that of their original and present families ^(o6).

Regarding the socio-professional classification of respondents (middle column), those that are (or were) industrial or farm workers are the greatest number (46%), followed by the operational employees (36%). The next group with statistical significance is the group of independent workers (13%).

The remaining socio-professional categories show residual values.

TABLE 12.

RESPONDENT’S OWN SOCIO-PROFESSIONAL CATEGORY, AND OF THE PRESENT AND ORIGINAL FAMILY

	SPC of the original family		SPC of the respondent		SPC of the present family	
	N	%	N	%	N	%
EDL	19	2,0	24	2,4	32	3,2
PTE	22	2,3	20	2,0	36	3,6
TI	275	29,1	129	13,0	165	16,7
EE	143	15,1	359	36,2	409	41,3
OAA	485	51,4	459	46,3	348	35,2

Considering the available information on the socio-professional categories of the Portuguese population as a reference, we can see an over-representation of the industrial and farm workers, and of operational employees, and an under-representation of entrepreneurs, leaders and liberal professionals, of technical staff, and of independent workers, among people with disabilities ^(o7). In other words, people with disabilities predominate in the social classes with fewer resources and have less relative presence in the social classes with greater resources.

^(o6) ELL: entrepreneurs, leaders and liberal professionals; TS: technical staff; IW: independent workers; OE: operational employees; IFW: industrial or farm workers (MACHADO ET AL., 2003).

^(o7) This result can be found in the final reports of the survey.

Additionally, a significant part of respondents with disabilities belong to the professional group of non-qualified workers (24% of the total) ^(o8).

Now, comparing the results of respondents with the socio-professional categories of the present and original family, besides the fact that the percentage differences are not significant, we can notice some specificity in the three structures which were described. The socio-professional categories of people with disabilities (in Table 12) are concentrated in the groups of lower resources, as mentioned: 83% are farm or industrial workers, and operational employees. Such concentration on the lower level of the socio-professional structure is less significant in the case of the present and original family, which respective equivalent values are 77% and 67%.

When we analyse the distribution in the categories with greater resources the situation is similar: the proportion of respondents with disabilities is always smaller than the proportion which is seen in their present families, and only shows a slightly higher value among entrepreneurs, leaders and liberal professionals when compared with the original families.

Therefore, we may conclude that people with disabilities, in general, are positioned in socio-professional categories of fewer resources compared to the global positions both of their present or original families.

In a direct comparison between the structures of the present and original families, we can see the same changes as those seen among the generations of the whole Portuguese society, as there is a decrease in the number of industrial and independent workers and an increase of operational employees, of technical staff, and of entrepreneurs, leaders and liberal professionals; however, the socio-professional structure of people with disabilities in general does not follow these changes, and whenever it does follow, it is not in the same proportion.

In order to deepen the analysis of what happened at the socio-professional level between the original family and respondents with disabilities, we carried out a joint analysis of the respective indicators (Table 13).

This table shows the courses and flows of socio-professional mobility between the generations of respondents and that of their parents. By analysing the percentages in the columns we see the differential weight of the socio-professional categories of the parents for each category of respondents. We can see that respondents which work in the industry or in the agriculture, or those that are operational employees, mostly come from families with the same socio-professional position (62% and 49%, respectively), followed by the parents as independent workers (23% and 26%).

Respondents working as independent workers have social origins mostly from the same category (57%), followed by that of the industrial and farm workers (33%).

(o8) The data for the Portuguese population is the following: ELL: 11,5%; TS: 14,6%; IW: 18,0%; OE: 28,1%; IFW: 27,8% (COSTA ET AL., 2000).

TABLE 13.

RESPONDENT'S OWN SOCIO-PROFESSIONAL CATEGORY AND SOCIO-PROFESSIONAL CATEGORY OF THE ORIGINAL FAMILY

Socio-professional category of the original family	Socio-professional category of the respondent									
	ELL		TS		IW		OW		IFW	
	%line	%row	%line	%row	%line	%row	%line	%row	%line	%row
ELL	0	0	31,6	30,0	5,3	0,8	42,1	2,4	21,1	0,9
TS	4,5	4,3	13,6	15,0	4,5	0,8	50,0	3,3	27,3	1,4
IW	5,5	65,2	1,1	15,0	25,1	56,6	31,6	25,7	36,7	22,9
OW	1,4	8,7	4,2	30,0	7,7	9,0	46,9	19,8	39,0	12,9
IFW	1,0	21,7	0,4	10,0	8,2	32,8	34,0	48,8	56,3	61,9

This data highlights that, in general, there is a replication of courses in the socio-professional categories of lower resources.

Respondents which work as technical staff, or entrepreneurs, leaders and liberal professionals, have, in some cases, originate from categories with lower resources, which point towards some intergenerational courses of ascending social mobility, however, the absolute values for the total individuals involved in the statistical analysis are small, and so are not enough to ensure a valid statistical conclusion.

Another way of analysing this table is by giving greater importance to the percentages lines, which show the way how the socio-professional categories of respondents are distributed for each category of the original family. We can see that for the industrial or farm worker parents, or operational workers, we mostly find respondents in the same socio-professional situation (56% and 47%, respectively) and that for the original families of independent workers, most of the respondents are either industrial or operational workers (37% and 32%, respectively).

These flows point towards processes of replication among categories with lower resources and descending courses of mobility between the parents' generation and that of the respondents.

For entrepreneur, leader and liberal professional parents, or technical staff, the socio-professional position of the respondents with greater weight is that of the operational employees, which suggests courses of descending mobility. However, as it has already been mentioned, the absolute values for the total individuals involved in the statistical analysis are too small, and so are not enough to ensure valid statistical conclusions.

Globally, this data confirms the remark made in the former comparison between the socio-professional structures of the respondent and of the present and

original families, and highlight a significant intergenerational replication of the socio-professional situation in the social classes with less resources and descending courses among categories of medium resources and categories of low resources.

Therefore, disabilities are factors that replicate unfavourable social conditions and of descending social mobility in Portuguese society.

Another relevant indicator for living social conditions is income. Table 14 contains data on the family monthly net income of surveyed people with disabilities. It highlights a situation of great economic precariousness: about 28% of families have, at the most, 403 Euros (equivalent amount to the national minimum wage), and almost half of them (49%) receive less than 600 Euros a month for their expenses. As the average number of individuals per family is of 2,4 for this population, the degree of economic precariousness is even more expressive.

TABLE 14. NET MONTHLY FAMILY INCOME (%)

PWD	
Up to 403 Euros	27,6
From 404 to 600 Euros	21,7
From 601 to 800 Euros	14,2
From 801 to 1000 Euros	7,9
From 1001 to 1200 Euros	4,6
From 1201 to 1600 Euros	2,4
From 1601 or more Euros	1,1
Does not know/does not answer	20,6

Considering as a reference the fact that in Portugal, in 2007, the poverty threshold corresponded to 360 Euros of income per adult (INE, 2007) it is very likely that a significant part of this population is actually below that threshold. As a matter of fact, people with disabilities are considered as particularly vulnerable to poverty and a significant proportion of this population integrates one of the typical categories of poor (CAPUCHA, 2005A).

After having analysed some of the most important data on social characterisation, following are some results related to cultural aspects, in order to assess the degree of disagreement with inequality and of pro-activeness of this population, and to which extent do they perceive the existence of discrimination, of opportunities and of support in their daily affairs.

As far as orientation regarding inequality, we can see that respondents with disabilities show greater disagreement with inequality (56%) than agreement (44%). However, such disagreement is less expressive than that which can be seen in the sample of the population of Mainland Portugal (71%).

TABLE 15. **ORIENTATION REGARDING SOCIAL INEQUALITIES**

	PWD		Population in Mainland Portugal	
	N	%	N	%
Obviously people are different from each other, but it is always possible to decrease social inequalities.	686	55,5	10720	71,4
Obviously people are different from each other, but social inequalities are inevitable.	547	44,3	4284	28,6
Does not know/Does not answer	2	0,2	1	0,0

As far as orientation for action, we can see that respondents are mostly proactive, in other words, for the most part they believe that one's position in society depends, above all, on having life goals and on the effort one makes in order to attain such goals (57%), and not so much on factors that can not be controlled by the individuals.

TABLE 16. **ORIENTATION FOR ACTION**

	PWD		Population in Mainland Portugal	
	N	%	N	%
Our position in society mostly depends on us having goals in life and on us endeavouring to attain them.	701	56,8	10848	72,3
Whatever we do, our position in society mostly depends on things we can not control.	532	43,1	4153	27,7
Does not know/Does not answer	2	0,2	4	0,0

However, also here, the weight of pro-activity is smaller than the one we see in the general population (72%).

Disagreement with social inequalities and pro-activity are therefore greater among people with disabilities, however, this majority is not very significant and is clearly smaller than the one found in the Portuguese population. The joint analysis of orientation regarding inequalities and orientation for action allows

us to classify respondents in terms of social orientation (CASANOVA, 2004) ⁽⁰⁹⁾.

The predominant social orientation among respondents with disabilities is that of autonomy, followed by orientations of heteronomy, independence, and resistance. The orientation of exclusion has a clear residual value. Besides the fact of autonomy being the orientation with the highest percentage (39%), it should be noticed that it is quite lower than the percentage found in the general population, which is clearly the majority.

TABLE 17. **SOCIAL ORIENTATION**

	PWD		Population of Mainland Portugal	
	N	%	N	%
Orientation for autonomy	483	39,1	8602	57,3
Orientation for independence	217	17,6	2246	15,0
Orientation for resistance	202	16,4	2116	14,1
Orientation for heteronomy	330	26,7	203	13,6
Orientation for exclusion	3	0,2	4	0,0

Comparing with the sample for the population of Mainland Portugal, we can still see that orientation for autonomy among people with disabilities has a relatively lower weight even though such weight is always greater in the remaining categories.

Globally, these results highlight certain socio-cultural traits in the population with disabilities, namely characterised by rejection of fatalism, resignation and exclusion, and, so, they show a support structure of individual and collective attitudes and actions for the improvement of their living conditions.

Within the scope of the survey, respondents with disabilities were asked about their perception of situations of discrimination in the different life contexts.

As can be seen in Table 18, between 92 and 97% answered that they never felt discriminated in any of the situations which were mentioned. The greatest percentage, as far as perception of discrimination, has to do with professional activity, but even in this situation the figure is clearly inexpressive.

We can also see that, besides everything, there is a slight difference between the first five situations and the remaining six: in the first ones, the percentages of perception of discrimination are slightly greater. The contents to which these first five situations refer to, have to do with relationships with institutions

(09) The contents for social orientations thus defined are the following: autonomy – proactive equalitarian; independence – proactive non-equalitarian; resistance – equalitarian non-proactive; heteronomy – non equalitarian non-proactive; exclusion – includes those that did not answer the questions.

(schools, health institutions, public services, credit institutions and insurance institutions) and with professional activity. The last six mostly refer to relationships with close entities in the respondent's daily affairs and with electoral experiences. In other words, perception of discrimination is globally residual and is even more insignificant when related to the interaction with the close environment around the respondent, than when it refers to the social plan in more abstract and institutional sense.

However, the small discrimination that people with disabilities seem to find in their daily life does not seem to involve significantly their family members and friends, whom are half way in the table of perceived discrimination.

TABLE 18. PERCEPTION OF SITUATIONS OF DISCRIMINATION (%)

	Almost always	Frequently	Seldom	Never
At the time of enrolment and/or when attending school	1,0	1,5	5,3	92,2
When seeking care at a hospital, clinic or health centre	1,0	1,6	4,2	93,3
In your professional activity	0,5	2,7	3,2	93,6
When served at a public department	0,4	1,9	3,0	94,6
When requesting credit at a bank or when trying to contract an insurance	0,8	1,3	2,8	95,1
In the relationship with family members and friends	0,2	1,2	3,1	95,4
When accessing and/or at a shop or shopping centre	0,4	1,5	2,2	95,8
When accessing and/or at a sports stadium, pavilion or other sports facility	0,3	1,2	1,7	96,7
At the time of enrolment and/or when attending an association or club	0,0	0,4	2,7	96,9
When accessing and/or at a cinema, theatre, museum or library	0,3	0,9	1,9	96,9
When exercising my voting rights	0,2	0,6	2,1	97,1

In the answers to specific issues of discrimination and lack of understanding at the workplace, percentages remain between 95 and 98% of those that feel they have not been discriminated, which is consistent with the former results. However, it should also be noticed that 5% say they did feel a little discrimination on behalf of their leaders/employers regarding their disabilities.

TABLE 19. PERCEPTION OF DISCRIMINATION AT THE WORKPLACE (%)

	Yes	No
Did feel little understanding from the side of their leaders/employers regarding their disabilities	4,6	95,4
Did feel little understanding from the side of their workmates regarding their disabilities	3,5	96,5
Did feel that the facilities and physical spaces are inappropriate	2,9	97,1
Did feel discrimination at their workplace	2,7	97,3
Did feel that the facilities and working material are inappropriate	2,0	98,0
Did feel that other people did not believe their disabilities were real	2,0	98,0

Naturally, the fact that respondents think that they are not discriminated does not mean that they are actually not. Much of the data from the social characterisation analysed above, in the comparison between respondents with disabilities and the Portuguese population, as far as relationships with work, school, etc., point in the direction of inequalities that may result, to a significant extent, from the existence of prejudice and of negative discrimination.

The apparently surprising fact of those being the object of such discrimination not perceiving or showing it may be due to a set of different factors.

First of all we must take into account that the social jurisdictions of lower resources, as is the case for the majority of people with disabilities, normally tend to develop a position of social conformism, which could be expressed through a type of conception that disabilities are an eminently personal tragedy, that must be personally managed, and as such, not a social issue for which society must provide. This justification of conformism seems to contradict former results on social orientation, which show that disagreement with inequalities predominates among this population. It is important to add that this last data refers to social inequalities, and that most probably, most people with disabilities do not consider that inequalities associated to changes in body functions can be interpreted as social inequalities.

As far as the factors that explain the absence of perceived discrimination, it is also probable that the questions on discrimination were understood by respondents as referring to people's behaviour in their daily lives, and really not to the way institutions and society as a whole function. And, in general, people with little resources, as is the case, usually do not know or do not feel competent to assess such logics of functioning. This interpretation agrees with the results that show less perception of discrimination in the interactions with their immediate environment and a positive assessment for the support offered by persons that are closer. These results are shown in Table 18 and Table 20, which shall now be analysed.

It was also requested that respondents position themselves in relation to the issue of support and opportunities, as described in Table 20.

TABLE 20. **PERCEPTION ON DAILY OPPORTUNITIES AND SUPPORT (%)**

	I agree absolutely	I agree	I disagree	I disagree absolutely	DNK/DNA
I feel I have the same opportunities to participate in civic and political life as people with no disabilities.	10,5	44,7	15,5	4,4	25,0
Persons with whom I come in contact in my daily life have facilitated or contributed towards my participation in society.	7,3	78,7	13,2	0,8	-

The data highlights that the majority (55%) of people with disabilities agree that they have the same opportunities to participate in civic and political life as the general population. This result is globally compatible with the fact that exercising the right to vote is the situation in which respondents feel less discriminated, as was already mentioned before. But, disagreement with equal political opportunities has a significant weight, involving about 20% of people with disabilities. Those that do not know or that do not want to answer this question are about 25%. This choice often means lack of information, and acceptance of ones lack of competence for expressing ones opinions, a typical attitude for social jurisdictions globally excluded from social life.

Agreement with the second statement is more significant (86%), showing a favourable opinion in what concerns support offered to people with disabilities for their participation in society, by those they come in contact with in their daily life.

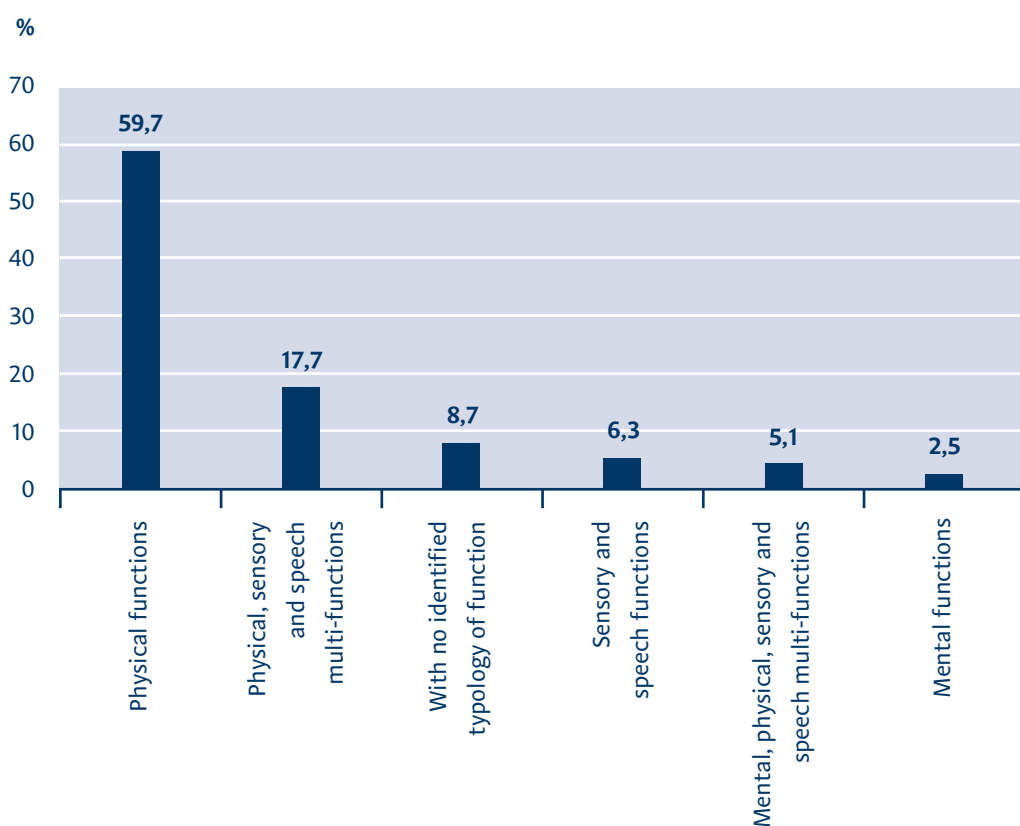
Comparing the data related with the statements made in Table 20, we may argue that this population, for the most part, seem to believe in equality of opportunities in terms of participation, but it mostly follow from the contributions made by people with whom they relate with, in their daily affairs, who actually facilitate such participation.

Respondents with disabilities are not just distinct in social and cultural terms. First of all, they are distinct regarding in time when they developed/acquired

the changes in their functions and their activity limitations, also by the type of changes in their functions ⁽¹⁰⁾ and by the type of activity limitations.

So, the age of development/acquirement of the changes of functions was analysed and whether or not they had been detected at birth and the conclusion was that the figure is about 4%. Therefore, we may conclude that the proportion of congenital disabilities is quite low, comparing to acquired disabilities.

GRAPH 2. PEOPLE WITH DISABILITIES ACCORDING TO THE TYPE OF CHANGES IN THEIR FUNCTIONS



(10) The changes in sensory and speech functions correspond to the aggregation of the changes at the level of visual, hearing, speech functions and of the changes in sensory and speech multi-functions (cases in which people have more than one change in the sensory and speech functions).

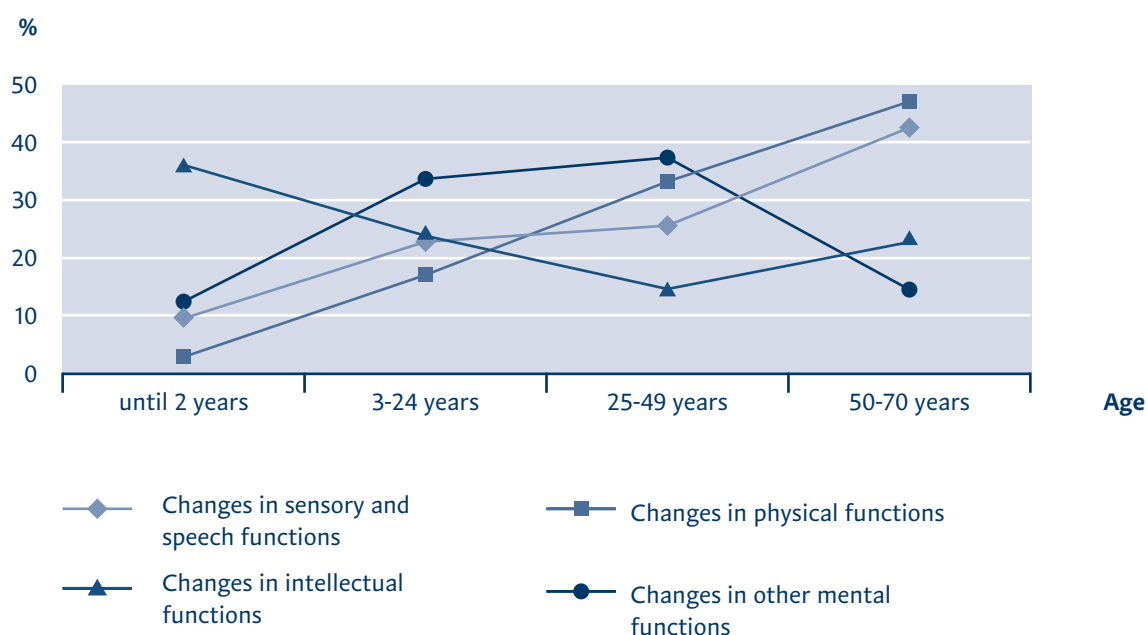
Changes in physical functions include changes of the cardiovascular, haematological, immunological and breathing systems, changes in the functions of the digestive, metabolic and endocrine systems, changes in the genitourinary and reproductive functions, on the neuromusculoskeletal and movement related functions, on the functions of the skin, hairs and nails, and changes in the physical multifunction (cases in which people have more than one change in physical functions)

Changes in mental functions include changes in intellectual functions and changes in other mental functions.

Multifunction categories include changes in several functions, specified by the name of each change. Lastly, the category with no identified typology of function integrates all individuals with multiple activity limitations and changes of functions but with no perceptible relationship between them.

In what concerns the type of changes of functions, those associated to physical functions are those that reveal greater expressiveness (60%). Then they are followed by functions involving combined changes in physical functions and in sensory and speech functions, still with significant expression (18%). The remaining groups have almost residual expression and changes associated to mental functions are those with the least weight in the surveyed population (3%).

GRAPH 3. AGE OF DEVELOPMENT/ACQUISITION OF CHANGES OF FUNCTIONS BY TYPE OF FUNCTIONS

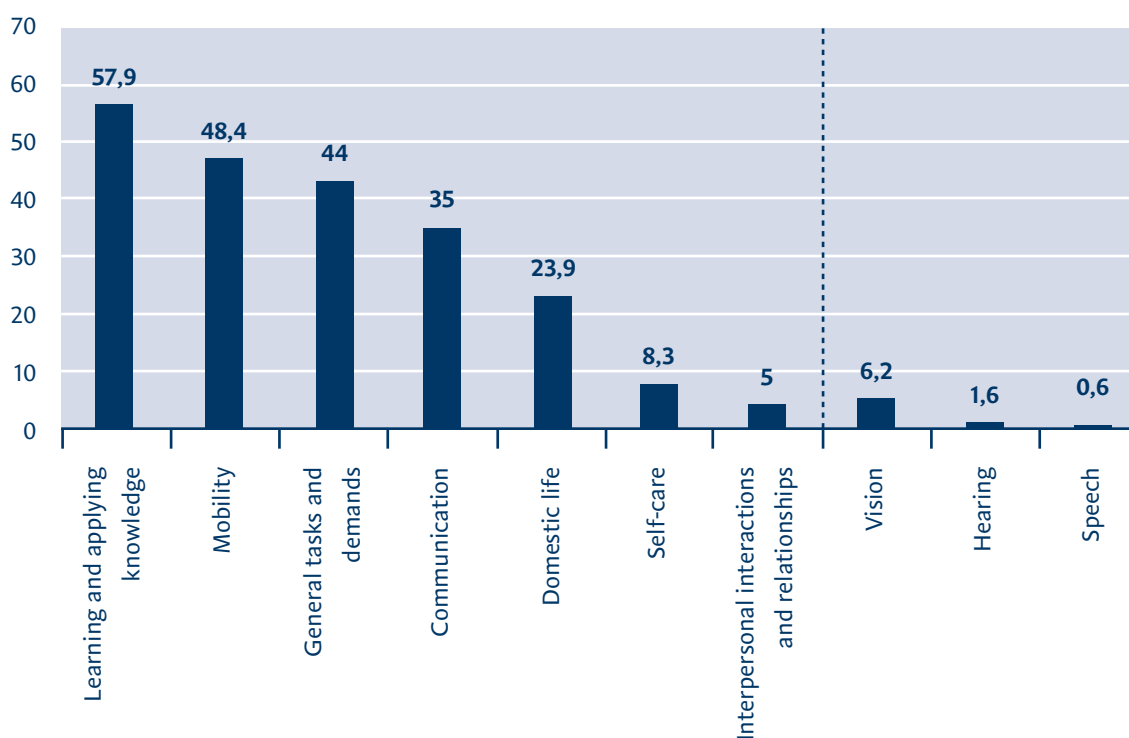


By considering the age of development/acquisition of the changes of functions (Graph 3), we can see that at the level of changes of physical functions there is a direct relationship with age, and there is a progressive and constant increase in the proportion of individuals along the life cycle. This direct relationship is equally visible in the changes of sensory and speech functions, even though we can see a more significant increase in the age group from 50 to 70 years, when compared with the age group from 25 to 49 years. On the other hand, changes in intellectual functions and in other mental functions (typologies which integrate mental functions) do not show this direct relationship with age. Changes in intellectual functions show significant incidence until 2 years of age, whereas changes in other mental functions have greater prevalence between 3 and 24 years, and from 25 to 49 years.

When addressing disabilities related to activity limitations, we chose to analyse separately the activity limitations related to vision, to hearing and to speech.

With the data collected from the survey, we concluded that such discrimination enriches the critical analysis of such data and enables a better analytical correspondence between changes in functions and activity limitations. In order to ensure coherence with the ICF, presentation of the three types of the above mentioned limitations is delimited by broken line (Graph 4).

GRAPH 4. PEOPLE WITH DISABILITIES ACCORDING TO THE TYPE OF LIMITATIONS OF ACTIVITY



In this domain of analysis, we can see a predominance of limitations of learning and applying knowledge (58%), of mobility (48%), of general tasks (44%), of communication (35%) and of domestic life (24%) (Graph 4).

On the other extreme, are the activity limitations which are less identified, as those associated to speech (1%), to hearing (2%), to interactions and to interpersonal relations (5%) and to vision (6%).

In other words, the global table, collecting changes in functions and activity limitations point towards a strong predominance of changes and limitations acquired along peoples lives, with predominance of physical functions. The most referred activity limitations include learning and applying knowledge, mobility and tasks, and general demands.

In summary, the results presented allow us to sketch a socially critical image of the population with disabilities.

It is a predominantly female, adult and aged universe, with very low levels of academic qualification – significantly lower than the national average –, globally excluded from the labour world, and those that did have work experiences show professional situations in the less qualified positions, and are part of intergenerational courses of replication of social classes with low resources or courses of descending social mobility, and are integrated in family contexts with low income, close to the national minimum wage.

From this global social profile we may say that in the type of frame of life this population lives in, there are several types of overlapping social inequalities, such as those which refer to access to a job, to professional qualification, to school, to unequal income and to inequalities associated to differences of gender and age. These inequalities indicate the existence of prejudice and discrimination in the Portuguese society regarding people with disabilities, and combination of socially unfavourable situations is a very strong factor for social exclusion.

Besides this general unfavourable condition, and very often, this condition of poverty, most of these people state disagreement with social inequalities and show a proactive orientation in their social life, even though in lesser degrees than the Portuguese population as a whole. A similar majority of people with disabilities believes that there are equality of opportunities to participate in civic and political life, but a much greater proportion refers the contribution of other people with whom they come into contact in their daily lives, as a relevant factor for such participation, which indicate that the participation of these people in Portuguese society is made easier by the support offered by people that are close to them, and not really by the institutional systems.

Against all the preceding empirical indicators, people with disabilities think they are not discriminated in Portuguese society, which can be understood as a trait of expected conformism in a population living for the most part on the fringe of social exclusion. But such conformism is not a result of their social orientations, in which disagrees with social inequalities and pro-activity clearly prevail. This paradox may result, probably, from the fact that people with disabilities do not consider that their disabilities may be seen as a social condition: so, it is a population with residual social awareness, involving, basically, the absence of information on such social condition.

REHABILITATION POLICIES AND LIFE PATHWAYS

The goal of the rehabilitation system is to offer people with disabilities greater participation in social and economic life, and the greatest autonomy possible, independently of the type of disability, or of its origin. In order to achieve that, the rehabilitation system is made up of a set of support systems and general and specific services for this population, in the different fields of education, health, employment, transportation, sports, etc. It also integrates a set of compensatory measures, translated as social welfare money allowances.

As mentioned previously, the second stage of the national survey had the purpose of analysing the relationship between the rehabilitation system and the life pathways of people with disabilities. Following, we shall present the results from that stage of the survey, organised in three parts: (1) characterisation of the type of people with disabilities that passed through this system (independently of the type of support and services they received), followed by the analysis of some of the support and services which were considered; (2) analysis of the relationship between passing through the system and life pathways, according to some fundamental domains of the Quality of Life model; (3) characterisation of the individuals that benefit from social income and of the type of income which is earned.

TABLE 21. **SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY GENDER**

	PWD with support and services			PWD without support and services		
	N	% row	% column	N	% row	% column
Male	138	40,1	39,7	206	59,9	30,5
Female	210	30,9	60,3	469	69,1	69,5

Thus, from the total people with disabilities, about 32% experience (or have experienced) support and services made available by the rehabilitation system. They are mostly women. However, considering the percentage weight of women, we can see that within the “gender” category, the percentage of men that have already accessed this type of services and support is greater than the percentage of women in 10%, which allows us to state that men are greater users or beneficiaries of services and support from the rehabilitation system. This data confirms other conclusions already drawn, and reveal a position of double disadvantage of women with disabilities.

Mostly, subjects aged between 18 and 49 years were the object of support and services offered by the rehabilitation system, while the age group from 60

to 70 years shows a smaller percentage. The fact that the rehabilitation system is quite young might explain this difference, since the system was just born in 1974, only the generation from 20 to 40 years could benefit from it for their whole life. For the elder generations, support and services did not even exist, and when they were actually launched, some of these measures did not have any repercussion before these generations, as they were measures aimed at the first stages of life, which the elder individuals had already overcome, such is the case with special education and vocational training. However, we can see that about 29% of individuals aged between 60 and 70 years obtained some support or service aimed at people with disabilities.

TABLE 22. SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY AGE GROUPS

	PWD with support and services			PWD without support and services		
	N	% row	% column	N	% row	% column
18 – 29 years	23	44,2	6,6	29	55,8	4,3
30 – 39 years	31	36,5	8,9	54	63,5	8,0
40 – 49 years	58	45,3	16,7	70	54,7	10,4
50 – 59 years	81	37,9	23,3	133	62,1	19,7
60 – 70 years	155	28,5	44,5	389	71,5	57,6

People with disabilities that did receive support and services supplied by the rehabilitation system, when comparing with those that did not receive such support and services, show higher percentages, in the most advanced education levels. Whereas, for the population that did receive support, the percentage of people that do not know how to write or read and that did not attend school is 18%, among those that did not experience this type of contact with the rehabilitation system, 26% do not know how to write or read, even if they do know, they did not attend school. On the other hand, 4% of people that did receive support were able to reach secondary education, and only 3% of people that did not pass through the rehabilitation system reached that same level.

The illiteracy rates also reflect these differences: as for the population that passed through the rehabilitation system, the illiteracy rate is 14% and, in the universe of people that did not pass through it, the figure is 18%.

TABLE 23.

SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY SCHOOL LEVELS

	PWD with support and services			PWD without support and services		
	N	% row	% column	N	% row	% column
I do not know how to write or read	49	29,2	14,1	119	70,8	17,6
I do know how to write or read, but I did not attend school	14	20,9	4,0	53	79,1	7,9
1st level of basic education	194	34,5	55,7	368	65,5	54,5
2nd level of basic education	41	38,3	11,8	66	61,7	9,8
3rd level of basic education	28	41,8	8,0	39	58,2	5,8
Secondary education	15	46,9	4,3	17	53,1	2,5
Medium/higher education	7	35,0	2,0	13	65,0	1,9

As far as the relationship with the labour world, some relevant differences can be found among both groups. Those subjects that have already received some support and services from the rehabilitation system show a lower rate of activity (26%) compared with those that did not benefit from the system (36%).

Another important piece of information to retain is that of the unemployment rate. Respondents that, to some extent, have passed through the rehabilitation system show an unemployment rate of 31%, whereas respondents that have never received any type of support or service from the rehabilitation system show a figure of 26%.

In order to analyse this data one must pay attention to two factors. On one hand, the individuals that access the rehabilitation system are mostly individuals from younger age groups, with coexistence of changes in sensory and speech, physical and mental multi-functions, and that present high limitations for performing any activities, which influences the differences seen between these two groups. The individuals that did not benefit from support and services from the rehabilitation system, do not have such a high level of limitations, and have greater chances of integration in the labour market. Simultaneously, because of belonging to more advanced age groups and because of having acquired their changes of functions at more advanced age, they were already integrated in the labour market when their acquired such changes, and also the labour market itself was in a more stable situation.

On the other hand, we should highlight the fact that this first analysis of the rehabilitation system, and as has already been mentioned, considers the different types of support and services of the system, which also influences the data

being presented. We consider as a passage through the rehabilitation system all respondents that mentioned that they had received at least one type of support and service from the system, independently of its nature, and so it includes individuals who received support for education, or attended medical or functional rehabilitation activities, etc., and not just those that received support in order to access the labour market (that shall be analysed later on, in this same chapter). Therefore, and just as an example, an individual may have passed through the system just because he received physiotherapy, however such fact may have not been determining for his access to the labour market.

In order to analyse the occupations of PWD, we need to keep these explaining factors in mind once again. We can see that the most representative professional groups of this population are the industrial workers, followed by non qualified workers and by administrative and service staff. In addition to the fact that this order is common to subjects that passed and that did not pass through the rehabilitation system, we can see some differences between both groups, as there is a greater proportion of non qualified and industrial workers among the subjects that accessed support and services from the rehabilitation system, whereas, less weight in the professional group of leaders and managers. The major difference to record has to do with farmers – only 10% of PWD that passed through the rehabilitation system are farmers, whereas there are about 18% of farmers in the group of respondents that have never passed through the rehabilitation system.

TABLE 24. **SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY OCCUPATION**

	PWD with support and services		PWD without support and services	
	N	%	N	%
Leaders and managers	11	4,1	26	5,1
Administrative employees and service staff	60	22,3	105	20,2
Farmers and qualified workers in agriculture and fishing	26	9,7	91	17,5
Industrial workers	7	36,8	15	34,5
Non qualified workers	73	27,1	118	22,7

Regarding their situation in their occupation, we can see that almost all individuals that had a professional activity were employed persons, independently of having had or not passed through the rehabilitation system. However, there are some percentage differences, and it can be seen that respondents that passed through the rehabilitation system, comparatively with those that did not, show lower percentages in the categories “owner” (2%; 3%) or “self-employed person” (9%; 14%).

It is among respondents with more fragile economic situations that we see a greater rate of coverage by the rehabilitation system, and we can see that it is in the interval from 404 to 1200 Euros that the coverage rate is greater, decreasing significantly after that interval.

As far as activity limitations, and as already mentioned, we can see that subjects with greater limitations are those that benefit the most from support and services of the rehabilitation system (41% against 32% with moderate limitations). These also have a greater weight in individuals with activity limitations related to speech, self-care, interactions and interpersonal relations, and domestic life. On the other hand, subjects with activity limitations related to vision, communication and hearing are those that have accessed the least services and support offered by the system.

TABLE 25. **SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY TYPES OF ACTIVITY LIMITATIONS**

	PWD with support and services		PWD without support and services	
	N	% row	N	% row
Self care	75	56,4	58	43,6
Interactions and interpersonal relations	35	46,1	41	53,9
Domestic life	132	44,0	168	56,0
Mobility	218	42,9	290	57,1
General tasks and demands	153	31,9	326	68,1
Learning and applying knowledge	181	29,7	429	70,3
Communication	105	28,6	262	71,4
Speech	16	61,5	10	38,5
Vision	20	28,6	50	71,4
Hearing	6	24,0	19	76,0

In terms of body functions, we see that, even in the type of changes with greater access to support and services from the rehabilitation system, the percentage of individuals do not reach 50%. In the different categories of changes in the functions which were studied, the percentages are low and somehow misadjusted, in some of the groups of changes in functions of greater incidence; we find the lowest percentage values, as in the case of changes in physical functions.

As already mentioned, the cases of changes in sensory and speech, physical and mental multi-functions, physical and sensory, and speech multi-functions are those that show the highest percentages in terms of experiences of support and services from the rehabilitation system. On the other hand, changes in sensory and speech functions are those that show the least use of the system.

TABLE 26. SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY TYPE OF CHANGES OF FUNCTIONS

	PWD with support and services		PWD without support and services	
	N	% row	N	% row
Sensory and speech functions	17	24,6%	52	75,4%
Physical functions	194	33,9%	379	66,1%
Mental functions	14	33,3%	28	66,7%
Sensory and speech, physical and mental multi-functions	48	48,5%	51	51,5%
Sensory and speech, and physical multi-functions	63	37,5%	105	62,5%
With no identified function type	12	16,7%	60	83,3%

When analysing the age of development/acquisition of changes, we see that those persons that developed/acquired such changes at birth, or during their first years of life, are those that resort the most to support and services from the rehabilitation system. Whenever such changes of functions are acquired at later periods in life, individuals tend to resort to such services and support in smaller degree, and there is a continuous decrease as the changes of functions are acquired at more and more advanced ages.

TABLE 27. SUPPORT AND SERVICES FROM THE REHABILITATION SYSTEM BY AGE OF DEVELOPMENT/ACQUISITION OF THE FIRST CHANGE OF FUNCTION

	PWD with support and services			PWD without support and services		
	N	% row	% column	N	% row	% column
Until 2 years	48	45,3	16,5	58	54,7	11,4
3-24 years	71	37,8	24,4	117	62,2	22,9
25-49 years	91	35,8	31,3	163	64,2	31,9
50-70 years	81	31,9	27,8	173	68,1	33,9

After analysing the social profile of the individuals covered by the specific support and measures aimed at people with disabilities, it is now the time to analyse the type of measures and support used in the fields of education, work and employment, assistive products and health care ⁽¹¹⁾.

Support and services aimed at people with disabilities in the field of education have the purpose of promoting education adjusted to the specific needs of this population.

As already mentioned, this type of support and services, which achieved great development after the 25th of April of 1974, was aimed at a specific stage of individuals. So, for the purpose of the present analysis, we only considered those born after 1968, i.e. people which were at school age at the time of development of the support and services for education, and which developed/acquired their disabilities before their 25 years of age, while possible beneficiaries of this type of support and services.

Within this “sub-universe” we can see that 5 individuals out of 43, in other words, about 12% of subjects, used some type of support and services in education, corresponding to only 5 cases. Out of these, about 3 individuals attended schools with special education, and 2 received specialised support until 12th grade, when they entered a school with regular education.

Still, and besides the absolute values of our data being quite low, and so we can not draw conclusions for the universe, we may mention that in general terms individuals that actually benefited from such support are mostly males, aged between 18 and 29 years, with high limitations for performing activities, with coexistence of changes in sensory and speech, physical and mental multi-functions. As for those subjects that did not benefit from support and services in education, we can see that individuals with changes in physical functions and individuals with no identified type of function did not benefit from any educational service or support.

Considering the limitations for carrying out a professional activity that might be imposed by any disabilities, it is fundamental that, within the scope of specific measures for this population, there are support and services aiming at promoting their access to the labour market.

In order to analyse these support systems and services, and since they were actually developed since the beginning of the 1980s, we opted for selecting for our analysis only respondents which were starting their entrance into the labour market during this period. Therefore, we only considered individuals that

(11) In this item we shall not analyse all the specific services and support for people with disabilities. A much more detailed analysis of these services may be found in the report “O sistema de reabilitação e as trajetórias de vida das pessoas com deficiências e incapacidades em Portugal” [The rehabilitation system and the life pathways of people with disabilities and impairments in Portugal].

developed/acquired their disability before 64 years of age, in other words, during their active age, that have or had a professional activity and that, in 1983 were 16 years old (this was the year when specific support for access to employment started with the creation of the Sheltered Work Centres, in Portugal). In this way, we can see that within this group, 6 respondents out of 58, benefit or benefited from some type of support or service for accessing the labour market, which corresponds to 10%. Out of these, 2 received vocational training at a support institution for people with disabilities, and 2 got a job through the Employment Centres, while just 1 respondent received specific support for people with disabilities and just 1 received vocational training at the Employment and Vocational Training Institute.

TABLE 28.
TYPE OF SUPPORT AND SERVICES FOR ACCESSING THE LABOUR MARKET

	N	%
Specific support for people with disabilities	1	16,7
Got a job through the Employment Centre	2	33,3
Vocational training at institutions for supporting disability	2	33,3
Vocational training at training centres of the IEFP [Employment and Vocational Training Institute]	1	16,7
Total	6	100,0

In spite of the fact that we can not draw conclusions for the universe due to the nature of the data, in general we can see that male individuals, aged between 30 and 40 years of age, are those that use the most the support system and services for accessing the labour market. This support is also more expressive in the professional group of service staff and sellers, followed by non qualified workers. Comparing both groups, we can see a greater rate of activity among subjects that benefited from support (72%), when comparing with those that did not have access to it (67%).

As far as limitations for activities and changes in body functions, there is a predominance of individuals with moderate limitations, centred on self-care, around performing activities in domestic life and communication. On the other hand, subjects with changes in mental functions and with coexistence of changes in sensory and speech, physical and mental multi-functions, are those that show greater values in mobilising such support and services, with the smaller percentages being centred on individuals with coexistence of changes in physical and sensory and speech multi-functions and on individuals with no identified type of function.

Among the different types of support offered by the rehabilitation system the main type of elements are assistive products, with the purpose of preventing, compensating, mitigating or neutralising the impairment, in order to enable full participation of the individuals in all daily activities.

About 19% of respondents needed or needs assistive products, according to the activity limitations they present. Out of these, about 77% mentioned that they are using it or have used it in the last years. However, 23% of the population with disabilities, in spite of requiring assistive products, did not use it. The main reasons presented by respondents for not satisfying this need were the financial conditions (21% mentioned the option “the assistive products they required was too expensive” and 15% mentioned the option “I requested financial support for the acquisition, but did not get it”) and the inexistence of appropriate assistive products (18% of respondents mentioned the option “there are no assistive products for my disabilities”).

Of all respondents that mentioned that they had required assistive products and that they actually benefited from it, we can see that assistive products for personal mobility (where we include wheel chairs, walking canes, other walking devices, etc.) are the mostly used (71%), followed by orthoses and prostheses and assistive products for personal care and protection.

TABLE 29. TYPE OF ASSISTIVE PRODUCTS USED

	Yes		No		Total	
	N	%	N	%	N	%
Assistive products for personal medical treatment	13	10,0	117	90,0	130	100,0
Assistive products for training in skills	6	4,6	124	95,4	130	100,0
Orthoses and prostheses	43	33,1	87	66,9	130	100,0
Assistive products for personal care and protection	20	15,4	110	84,6	130	100,0
Assistive products for personal mobility	92	70,8	38	29,2	130	100,0
Assistive products for housekeeping	5	3,8	125	96,2	130	100,0
Furnishings and adaptations to homes and other premises	9	6,9	121	93,1	130	100,0
Assistive products for communication and information	–	–	130	100,0	130	100,0
Assistive products for handling objects and devices	4	3,1	126	96,9	130	100,0
Assistive products for environmental improvement, tools and machines	1	0,8	129	99,2	130	100,0
Assistive products for recreation	1	0,8	129	99,2	130	100,0

Assistive products for communication and information did not have any user, while there are residual percentages in assistive products for environmental improvement, tools and machines (1%) and assistive products for recreation (1%).

Men are those that use most assistive products, comparatively with women. As far as age, respondents aged between 40 and 59 years are those that present greater percentages in the use of these facilities. On the other extreme, are respondents between 30 and 39 years, even though with a high percentage of use.

The level of impairment manifested by respondents does not seem to be a relevant factor for the use of assistive products. As a matter of fact, both respondents with moderate impairments as well as those with high level of impairment show percentages of use quite high and quite similar.

Therefore, when analysing the different activity limitations we can see that for all of them there are high percentages of use of assistive products.

As far as changes in body functions, we can see that individuals with coexistence of changes in physical, sensory and speech multi-functions, and with changes in physical functions are those with greater percentage of use of this type of facilities.

Medical and functional rehabilitation is in close connection with assistive products and has a fundamental role for promoting physical and emotional well-being of people with disabilities.

36% of respondents mentioned that they attended these types of sessions as they felt the need for medical and functional rehabilitation, whereas 64% said they had never done it. The main reasons presented were lack of financial conditions and lack of information.

Among individuals that did receive medical and functional rehabilitation, most of them just attended one or two rehabilitation sessions (62% and 15%, respectively), and about 12% of individuals with disabilities said that they attended four or more of this type of sessions.

Among the different existing medical and functional rehabilitation services, physiotherapy takes a very relevant position, as about 96% of people with disabilities that attended medical and functional rehabilitation received this type of service.

TABLE 30.
TYPE OF MEDICAL AND FUNCTIONAL REHABILITATION SERVICE USED

	N	%
Physiotherapy	153	95,6
Speech therapy	2	1,3
Occupational therapy	3	1,9
Does not know/does not answer	2	1,3
Total	160	100,0

The number of respondents attending speech therapy sessions or occupational therapy is quite residual, with percentages around 1% and 2%.

Considering the factor gender, we can see that even though with little difference, men were those who attended more medical and functional rehabilitation sessions. And as far as age, the younger individuals (especially those aged between 18 and 29 years) are those that more frequently attended such sessions. The smallest percentage is for subjects aged between 30 and 39 years.

When considering the level of intensity of the activity limitations, we can see that individuals with higher limitations are those that more frequently attend medical and functional rehabilitation sessions.

As a consequence of physiotherapy being the most attended type of medical and functional rehabilitation service, respondents with activity limitations in terms of self-care, mobility and domestic life, show higher percentages of access to this type of services.

However, activity limitations related to speech are those with the greatest percentages of attendance of medical and functional rehabilitation sessions. The high percentage of people attending these sessions is partially due to the fact that this type of limitation generally coexists with other ones.

Such can also be confirmed if we consider changes in body functions, as it is among individuals with coexistence of changes in sensory and speech functions, physical functions and mental functions that we observe the highest percentages of attendance of medical and functional rehabilitation sessions. This type of rehabilitation also found high expression among individuals with changes in physical functions, followed by those with coexistence of changes in physical functions and in sensory and speech functions.

Participation and sociability

The issue of rights and social inclusion of people with disabilities has been analysed along the present chapter, and we have seen that this population lives within a framework of overlapping of several types of social inequalities, as those referring to basic issues such as access to the labour world, professional qualification, education, among others. Now, in the present item we want to explore other dimensions of rights, namely the fulfilment of roles and functions in public life, belonging to social networks, perception of control and efficacy over collective phenomena and the degree of openness of institutions to social participation.

As far as fulfilment of roles and functions in public life, we can see that most people with disabilities voted for the parliamentary elections of 2005 (78%), actually revealing a degree of political participation (as far as voting is concerned) relatively higher than the general Portuguese population. Within the group of subjects that did not vote, we see a greater weight of individuals that passed through the system (both in the case of those that did not vote, as in the case of those that were not registered for voting), which just once again reinforces the idea that those that pass through the system are the most serious cases of exclusion/vulnerability.

TABLE 31. VOTING FOR PARLIAMENTARY ELECTIONS IN 2005

	PWD		PWD with support and services		PWD without support and services	
	N	%	N	%	N	%
Voted	697	78,4	248	71,3	513	76,0
Did not vote	176	19,8	84	24,1	144	21,3
Was not registered for voting	5	0,6	10	2,9	10	1,5
Does not know/ does not answer	11	1,2	6	1,7	8	1,2

However, if we analyse other forms of participation in public life we can see that, on one hand, social and political participation of people with disabilities is quite small, and that, on the other hand, subjects that have already received support and services from the rehabilitation system reveal practices or intentions of participation which are more frequent than those that did not receive any support or services. This evidence is quite common in the different situations that were mentioned – when signing a petition, when writing a letter to a newspaper, when taking part in a strike, or when participating in initiatives for defending human rights.

Similar results were obtained when analysing participation in associations. The percentage of people that do participate in associations, organisations or organised collective groups is quite small. However, once again it can be confirmed that there is a greater participation by subjects that have already passed through the rehabilitation system, except for the cases of neighbours' associations, consumers' associations and religious associations.

TABLE 32. PARTICIPATION IN ASSOCIATIONS OR ORGANISED COLLECTIVE GROUPS (%)

	PWD	PWD with support and services	PWD without support and services
Sports club	2,8	3,2	2,2
Environmental or animal rights organisations	0,1	0,3	0,0
Organisations for retired people or beneficiaries from the social welfare system	0,6	0,9	0,3
Political party	0,7	0,9	0,4
Professional organisation	0,3	0,3	0,3
Consumers' association	0,2	0,0	0,3
Cultural, musical, dance or theatre association	1,3	2,6	0,4
Neighbours' association	0,6	0,3	0,6
War victims, war veterans or ex-soldiers association	0,1	0,3	0,0
Labour unions	0,2	0,6	0,0
Religious association	8,9	4,9	9,8
Associations related with a disease or a disability	1,0	3,4	0,3

On the other hand, when we analyse the degree of participation of the whole set of people with disabilities, religious, sports and cultural associations are those with greatest representation, and associations related with the disease or disability, as the second type of association in which people most participate.

As far as the type of participation, we can see that people with disabilities participate in a passive more way than in a really active one, in other words, they attend meetings and act as volunteers, and very few of them actually regularly plan meetings, prepare discourses, etc. These differences increase even more within the group of subjects that passed through the rehabilitation system, in which the only form of participation that stands out, when comparing with those that did not pass through the system, is voluntary work (29% and 27%, respectively).

TABLE 33. **TYPE OF PARTICIPATION** (% in column)

	PWD	PWD with support and services	PWD without support and services	
Do you participate in meetings	Sometimes	40,8	17,1	23,8
	Never or almost never	45,8	73,2	60,7
	DNK/DNA	13,3	9,8	15,5
Do you plan or chair meetings	Sometimes	28,4	14,6	16,7
	Never or almost never	57,5	80,5	64,3
	DNK/DNA	14,2	4,9	19,0
Do you prepare or write discourses before meetings	Sometimes	23,4	2,4	16,7
	Never or almost never	62,3	90,2	66,7
	DNK/DNA	13,3	7,3	16,7
Do you write texts for decision making	Sometimes	25,1	7,3	17,9
	Never or almost never	62,5	87,8	65,5
	DNK/DNA	12,5	4,9	16,7
Do you participate as a volunteer	Sometimes	42,5	29,3	27,4
	Never or almost never	48,8	65,9	57,1
	DNK/DNA	11,7	4,9	15,5

As far as openness of institutions, we tried to analyse to what extent do respondents agree or not with the existence of certain specific measures for people with disabilities, whether they feel that they have more or less opportunities for participating in political life and whether they have more in common with people with disabilities or with people with no disabilities.

Most individuals agree with the existence of specific measures for people with disabilities and agree with the fact of not having the same opportunities as all the others. The only statement that did not meet consensus is that of affinities, in other words, some respondents feel they have more in common with people with disabilities than with people with no disabilities. Comparing both groups of respondents, those with and those without experience of contact with the services and support of the rehabilitation system, allows us to say that those subjects that accessed the system show a greater degree of agreement with the questions made to them, as we can see in Table 34.

TABLE 34. **OPENNESS OF INSTITUTIONS** (% in column)

		PWD	PWD with support and services	PWD without support and services
There should be some vacancies higher education just reserved for PWD	Agrees	75,6	85,9	70,2
	Disagrees	6,2	1,7	8,1
	DNK/DNA	18,2	12,4	21,6
PWD should have priority in public tenders for admission of Public Servants	Agrees	57,9	70,4	53,0
	Disagrees	14,7	10,1	16,1
	DNK/DNA	27,3	19,5	30,8
I feel I have the same opportunities for participating in civic and political life as people with no disabilities	Agrees	55,2	60,9	53,0
	Disagrees	19,9	25,0	17,8
	DNK/DNA	25,0	14,1	29,2
I have more in common with people with disabilities than with people with no disabilities	Agrees	35,1	53,4	31,7
	Disagrees	39,4	31,9	38,5
	DNK/DNA	25,5	14,7	29,8

Still in this same field of analysis, of opinions of subjects with disabilities, we tried to identify their position/preferences on the passive or active orientation of social policies. We concluded that most part (46%) adopts a totally proactive orientation, considering that “the appropriate conditions should be created so that everyone can have a professional activity”. However, the second choice (32%) points towards a preference for a totally passive system, in which PWD should receive from the State and from the social welfare system allowances that may fully ensure their subsistence. Lastly, we find those that adopt a combined strategy (21%), in other words, that prefer that passive and active policies coexist simultaneously, by which the State should actually pay some allowances so that people with disabilities may face their difficulties, even though persons with disabilities they should also act in order to find a professional activity.

The option for an active approach stands out slightly in the group of subjects that have already accessed support and services from the rehabilitation system. Whereas, for this group 47% are in favour of active measures, in the group of those that did not attend any services from the system, the percentage is 45%.

When analysing the respondents' social networks, we can see that, in average, answers are situated in range 3 and 5, for direct contact ⁽¹²⁾, and 3 and 6, for indirect contact, which means that individuals, in general, keep regular contact with family members, friends and neighbours.

TABLE 35. **SOCIAL NETWORKS**

		AVERAGE ANSWERS		
		PWD	PWD with support and services	PWD without support and services
Direct contact	Children	4,8	4,8	4,8
	Parents	4,3	4,4	4,2
	Siblings	3,5	3,7	3,4
	Other relatives	3,2	3,4	3,1
	Best friend	4,3	4,5	4,2
	Neighbours	4,7	4,9	4,7
Indirect contact	Children	5,8	6,1	5,7
	Parents	5,3	5,5	5,2
	Siblings	4,2	4,6	4,1
	Other relatives	3,8	4,2	3,6
	Best friend	4,5	4,8	4,4
	Neighbours	3,2	3,0	3,3

Therefore, children and neighbours take up the most significant position in the individuals' social networks, even though, in the case of indirect contact, neighbours are replaced by parents.

In turn, when comparing between individuals that benefited and that did not benefit from support and services from the rehabilitation system, we can conclude that those that actually benefited, in average, have greater intensity of contacts.

Lastly, we considered relevant to analyse to what extent are people with disabilities actually aware of some legislative measures developed within the scope of disability. More than half the population with disabilities is unaware of the measures presented to them, and we could see that “elimination of architectural barriers”, “complementary payment for assistance by a third person” and “exemption of income tax for certain persons with disabilities” are the most known by this population.

⁽¹²⁾ The choices for direct contacts range from 1 – “I have no contact” and 6 – “More than once a day”. As for indirect contact, they range from 1 – “I have no contact” and 8 – “More than once a day”.

TABLE 36. LEGAL INITIATIVES FOR PEOPLE WITH DISABILITIES (%)

		PWD	PWD with support and services	PWD without support and services
Elimination of architectonic barriers in public buildings, collective facilities and public ways	Is aware	48,4	60,6	42,8
	Is not aware	51,6	39,4	57,2
Programme “Accessible Beaches”	Is aware	33,9	45,4	29,2
	Is not aware	66,1	54,6	70,8
Pension for adaptation to ones’job	Is aware	26,1	30,2	23,9
	Is not aware	73,8	69,8	76,1
“Design for All” ICT products	Is aware	16,6	17,8	16,9
	Is not aware	83,4	82,2	83,1
Complementary payment for assistance by a third person	Is aware	40,8	50,9	36,0
	Is not aware	59,1	49,1	64,0
Concept of “Special Needs Education”	Is aware	33,1	44,8	27,8
	Is not aware	66,9	55,2	72,2
Foster care for adults with disabilities	Is aware	26,7	31,0	24,9
	Is not aware	73,2	69,0	75,1
Early intervention	Is aware	18,5	23,3	16,8
	Is not aware	81,5	76,7	83,2
Exemption of income tax for certain persons with disability	Is aware	42,4	53,4	38,0
	Is not aware	57,6	46,6	62,0
System of financial support for purchasing assistive products	Is aware	29,0	39,4	24,6
	Is not aware	71,0	60,6	75,4

However, it should be mentioned that within the group of respondents that have already received or are receiving support and services from the rehabilitation system, the percentage values of awareness of the measures presented to them is quite higher, both in face of the population with disabilities as a whole, and in face of the individuals that did not access support and services from the

rehabilitation system, whom actually evidenced a significant lack of information at this level, expressed in the values under the option “Is not aware”.

Self-determination and personal development

The questions related to self-determination and personal development aim at determining the degree of perception of people with disabilities, on the one hand, on their own well-being in physical and emotional terms, and, on the other hand, to understand their feelings of personal and social autonomy.

As far as physical and emotional well-being we can see that, in average, answers were situated between 2 and 3 ⁽¹³⁾, meaning that, in general, respondents are mostly satisfied with themselves and with their life. If we analyse the differences between people benefited and not benefited by the rehabilitation system, we can see that subjects that had access to support show greater agreement and satisfaction regarding the questions presented to them. The capacity to better accept disability and changes in the relationships with people close to them correspond to the domains where there are more differences between both groups, while among those that benefited from services and support from the system, the average of answers is significantly higher.

(13) *The options for answering range from 1 – “I absolutely disagree” to 4 – “I absolutely agree”.*

TABLE 37. **PHYSICAL AND EMOTIONAL WELL-BEING**

	AVERAGE ANSWERS	
	PWD with support and services	PWD without support and services
In general I feel satisfied with myself	2,89	2,80
My autonomy for performing day-to-day tasks has improved	2,72	2,70
I am able to overcome obstacles and difficulties inherent to my limitations	2,80	2,76
I am able to outline and fulfil plans and goals for my life	2,87	2,77
The number of people with whom I have contact has been increasing	2,67	2,58
My relationships with those close to me have improved	2,89	2,70
Presently it is easier for me to accept my disability than it was in the past	2,87	2,62
As time goes by I am becoming a more confident person on my own capabilities	2,80	2,67
A feel less and less lonely	2,76	2,62
People with whom I come in contact in my daily life have facilitated or contributed towards my participation in society	2,99	2,85

As far as satisfaction with ones material and financial life, and considering that most respondent’s families have very low monthly net income, we can see that the levels of dissatisfaction are slightly higher, comparing with the former questions. Still, we can see a decrease in those levels of dissatisfaction in the group of subjects that received support and services from the system.

TABLE 38. **SATISFACTION WITH MATERIAL AND FINANCIAL LIFE**

	PWD with support and services		PWD without support and services	
	N	%	N	%
Not at all satisfied	34	9,8	82	12,1
Little satisfied	144	41,4	302	44,7
Satisfied	162	46,6	284	42,1
Very satisfied	4	1,1	5	0,7
Does not know/ does not answer	4	1,1	2	0,3

In order to assess the level of perception of respondent's personal initiative in their lives, we asked them who they thought were the main responsible persons for their decisions. In general, they considered that the main changes that occur in their lives are a result of their own decisions (89%) and not by guidance or indication of any third parties. We did not find any relevant differences between individuals that had received support and services from the rehabilitation system and those that had not.

Social allowances

Within the rehabilitation system, besides the type of support and services already mentioned, there is a set of monetary allowances from the social welfare system which are considered as integral parts of that same rehabilitation system, considered as passive policies of compensatory nature. These allowances are awarded by the Social Welfare System, with the general goal of protecting those citizens that find themselves in situations of diminished means of subsistence or diminished capacity for working, with the purpose of promoting their personal autonomy. The list of this type of monetary allowances includes a diversified set of situations, which in some cases can be cumulative.

By analysing the data which was obtained, we can see that about 19% of the population with disabilities receives at least one social allowance integrated in the rehabilitation system. From the whole set of social allowances, the one with greater expressiveness among people with disabilities is the Disability Pension, followed by the Social Disability Pension.

TABLE 39. SOCIAL ALLOWANCES

	Yes		No	
	N	% row	N	% row
Disability Pension	123	21,9	439	78,1
Social Disability Pension	38	6,8	524	93,2
Complementary Payment for Assistance by a Third Person	5	0,9	557	99,1
Special Pension for Disabled Tenants	2	0,4	560	99,6
Benefit for the Care of Severely Disabled or Chronically Ill Persons	1	0,2	561	99,8
Monthly Lifelong Pension	1	0,2	561	99,8
Complementary Payment for Dependant Persons	1	0,2	561	99,8
Pension Supplement for Dependant Spouse	-	-	562	100,0
Extraordinary Long Term Care Supplement	-	-	562	100,0
Supplement to Family Benefit for Handicapped Children and Young Persons	-	-	562	100,0
Occupational Disease Benefits	-	-	562	100,0

As we can see in the table above, there is a set of social allowances with a more specific scope, aimed at more specific situations, which have residual frequencies. On the other hand, allowances such as the Pension Supplement for Dependant Spouse, the Extraordinary Long Term Care Supplement, the Supplement to Family Benefit for Handicapped Children and Young Persons, and the Occupational Disease Benefits have no recorded cases.

Males, with disabilities, are those that benefit the most from social allowances. Simultaneously, the younger age groups (ages between 18 and 29 years) are those where we can see a greater incidence of social allowances. On the other hand, with the lowest percentage are people with disabilities aged between 60 and 70 years, benefiting from other types of allowances.

As far as characterising the activity limitations and their respective intensity, in general, social allowances benefit individuals with serious activity limitations

for performing their daily tasks and in social interactions. On the other hand, people with speech limitations are those with the greatest percentage of benefits from social allowances, followed by those with limitations in self-care activities. Simultaneously, personal interactions and relationships, and performance of activities related to domestic life also have significant percentage values. On the opposite extreme are people with hearing and communication limitations, with the smallest percentages of benefits from social allowances.

In turn, as for changes in body functions, the weight of social allowances is quite visible for individuals experiencing coexistence of changes in sensory and speech functions, physical functions and mental functions. With a similar figure are people with changes of mental functions. This data agrees with the characterisation made for activity limitations, as respondents with changes in mental functions, or combined in sensory and speech functions, physical functions and mental functions, are those with more limitations in their daily activities and in their interpersonal interactions and relationships, and so they receive the most social allowances.

As far as the age of development/acquisition of the first change of body functions, we can see that those that identified these changes as having occurred before the second year of age, they have the greatest percentages of benefits from social allowances. And these percentages gradually decrease as the age of development/acquisition of changes increases.

In summary, out of the total people with disabilities in need of receiving support and services from the rehabilitation system, the rate of coverage goes slightly above 30%. We should however safeguard that the rehabilitation system is quite recent and that people with disabilities considered herein are above 18 years, which means that, for the universe under study, only subjects aged between 18 and 30 years were able to benefit from the system along all their lives, and so it is expectable that for younger individuals (below 18 years, and not considered in the present sample) the rate of coverage is higher for some components.

The results presented herein allow us to define the profile of the user of services and support from the rehabilitation system. Mostly, it is a young, male universe, with congenital changes of functions, especially in mental functions and in sensory and speech, physical and mental multi-functions ⁽¹⁴⁾. This user profile and the characterising data which was collected

(14) The exception has to do with users of assistive products that are mostly individuals with changes in their physical functions.

seem to reveal some global disagreement of the rehabilitation system in face of the characteristics of the population with disabilities it's supposed to serve, since the general picture recorded points towards a strong predominance of disabilities acquired throughout the persons life, in which most of the changes relate to physical functions. As far as the types of services and support from the rehabilitation system, we could see that assistive products and medical and functional rehabilitation are those most used by subjects. On the other hand, vocational training and, in general, measures to support access to the labour market have little expression in terms of mobilisation.

The population that access or that accessed the services and support from the rehabilitation system also present different characteristics from those that did not. They show higher educational qualifications, smaller presence in the labour market (probably explained by the type of profile of the persons covered by the system), and professional integration in the less qualified groups. They also show greater levels of satisfaction in face of their general life, and in face of their material and financial condition.

As far as political, social and associative participation, individuals that have already received services and support from the rehabilitation system reveal practices or intentions of participation in public life much more active than subjects that never passed through the rehabilitation system, even though the type of participation is more of a passive nature. These more active types of attitudes and behaviours are transversal to other areas, namely regarding awareness of legislative measures within the scope of disabilities, and adoption of a proactive approach in face of the capacity of independence of people with disabilities. As far as social allowances, for the most part they benefit individuals with changes in body functions of congenital nature, which actually are their main source of income.



Chapter 6.

**The rehabilitation system
in Portugal: state of the art**

The effective progress we have seen in Portugal in the last decades enables us to identify a set of domains and challenges of development, in terms of understanding the issues, the conceptual models and the perspectives of intervention, formulation, organisation and operationalisation of policies, programmes and interventions, involvement and participation of stakeholders, as well as the modes of organisation and distribution of responses, allocation of resources, management of the system and of its effects.

The present period could be characterised as a moment of paradigm shift, in which some elements of the new conceptual and policy models are already evident, while coexisting with conceptual and practical structures from the former models, strongly rooted in some policy sectors and in some institutional practices, and less present in other sectors and other practices.

Within the context of modelling policies and practices for the future, that must obviously be anchored in the experience from the past, it is fully pertinent to carry out a critical review of the path that was followed, of the progresses that were made, in order to confront them with the new trends and the new conceptual and political references, to identify the options to make and to propose ways forward. By wisely balancing the passed and the present-future, with clearness and determination, we shall find the main guidelines for a new vision and for a new strategy for the next generation.

A PATH OF PROGRESS

Policy and ideology

In the period before 1974, intervention within the scope of disabilities in Portugal was not considered as a dimension for work. Being born with, or acquiring any disability, were seen as the person's own misfortune, and at times, also the misfortune of those around them. Isolation, marginalisation and exhibiting changes in body structures and functions, with the aim of obtaining alms as one's livelihood were in many cases the path of life (generally a short one) of these people. In terms of options of survival, all there was was private support – for people/families with more economic resources –, begging alms, or receiving charity from charity institutions. So, there was no political concern for this issue, nor any ideology.

From those times, to our days, Portugal has seen a deep transformation, namely in terms of culture of organic and institutional solidarity. The translation into Portuguese (in 1989) of the International Classification of Disability (formu-

lated by the World Health Organisation, in 1976), which supplied a conceptual definition; the recommendation 86/379/CEE, defining the role of the European Social Fund as an instrument of financial support for policies addressing equal rights and opportunities in terms of employment and vocational training; and the creation of the first Law on the prevention, rehabilitation and integration of people with disabilities (in 1989), where the idea of rehabilitation as integration is stressed, were the “main policy instruments for the sector and which crossed the whole period until the year 2000, and which enshrine the principles of universal rights and obligations, of global intervention, participation, integrated policies, information, pre-eminence of solidarity and equality of opportunities. Rehabilitation started to be seen as a global and continuous process, aiming at the person’s independence. The State takes up the responsibility of ensuring the appropriate policies, for which it defines and coordinates cooperation with the families, the organisations and the persons” (CAPUCHA ET AL., 2004).

In a synthetic approach, we could say that policy and ideology, as far as disabilities is concerned, went through the following stages, while coexisting at different moments (IBIDEM, adapted):

TABLE 40. POLICY AND IDEOLOGY – A PROGRESSING CONTINUUM

Before 1974	<ul style="list-style-type: none"> • Disability as “fatalism”. • Right to social welfare and rehabilitation. Rehabilitation as a global and continuous process for “compensating”, for overcoming handicaps of performance, and to enable participation/integration and autonomy.
At present	<ul style="list-style-type: none"> • Rehabilitation as a double process of “compensation” and transformation, aiming at “accessibility” and integration in current services.

From plain assistance aiming at just satisfying the most basic needs, and subsistence, until the recognition of civic, political and social rights of people with disabilities, was a long path of evolution, strongly pushed by Portugal joining the, at the time, European Economic Community (EEC), which enabled/fostered:

- the adoption of the social and political organisation models as references for national actions in several domains of activity of the State, of companies, of organisations, families and the persons themselves;
- the development of processes of coordination of economic, employment, education, solidarity and social welfare policies;

- the development of a set of infrastructures and policies, favoured by the financial flow coming from the European Union.

Programmes and measures

In line with the political and ideological evolution, even if with the usual time lag, programmes and measures also underwent a strong transformation between the period before 1974, and present times.

At the date of the first reference, protection, rather partial and incipient, was based on work insurances. As far as rehabilitation, and more specifically in the physical and functional areas, there was some progress, as a result of the colonial war. However, expansion of programmes and measures, namely in terms of social protection and health, only occurred during the period after the 25th of April, 1974.

Extension of the issue of disability to other fields occurred shortly after, having started by the dynamics of education, strongly pushed by the associative movements of parents, children and youngsters with disabilities. Another sign of enlargement appeared with the inception of the Employment and Vocational Training Institute, in 1979, right away with a service for Rehabilitation and Employment of Disabled Persons, from where we can conclude that, in the perspective of political decision makers, availability of financial means in order to ensure survival was not everything for the quality of life of people with disabilities, thus emphasising the relevant role of professional integration, namely in terms of personal well-being and social integration. Ever since then, the rehabilitation system has been significantly guided towards issues of education, initial vocational training and access to the labour market.

In the mid 1990s, the need to develop sectorial articulation was highlighted, namely between education, employment, social welfare and health, emphasising coordination of policies and programmes, even though as far as institutional and system practices the levels of coordination and articulation were quite incipient. Simultaneously, the first traits of the tendency for integration of these programmes and measures within the scope of general political programming started to appear.

The dynamic trend for transforming the absence of programmes and measures into their more comprehensive formulation, and integration into the current programmes, was global based on the following steps (IBIDEM, adapted):

TABLE 41. PROGRAMMES AND MEASURES – A PROGRESSING CONTINUUM

Before 1974	<ul style="list-style-type: none"> • Charity and family solidarity. • Priority for educating a new generation. • Launching of infra-structures, training of technical staff, formatting framework of measures. • Structuring of the system, continued training of staff, incorporation of knowledge and innovation of methodologies. Specialised and segmented services. Technical innovation in work processes. • Development of the system, incorporation of knowledge, and innovation of methodologies.
At present	<ul style="list-style-type: none"> • Integration of responses in the current structures, in some policy sectors.

As far as generation and updating of legislation and regulations, a significant progress was also seen, namely in the Portuguese Constitution plus two General Laws: the first one, the General Law for Prevention, Rehabilitation and Integration of People with Disabilities (Law nr. 9/89, dated from the 02nd of May); and the second one, the Law nr. 38/2004, dated from the 18th of August, defining the general bases of the legal regimen of prevention, habilitation, rehabilitation and participation of people with disabilities. Other laws were also developed related to sectorial policies. Even if not with a similar development, at the level of programmes there was also significant progress, which maximum expression was the 1st Action Plan for Integrating People Disabilities (Resolution from the Council of Ministers nr. 120/2006).

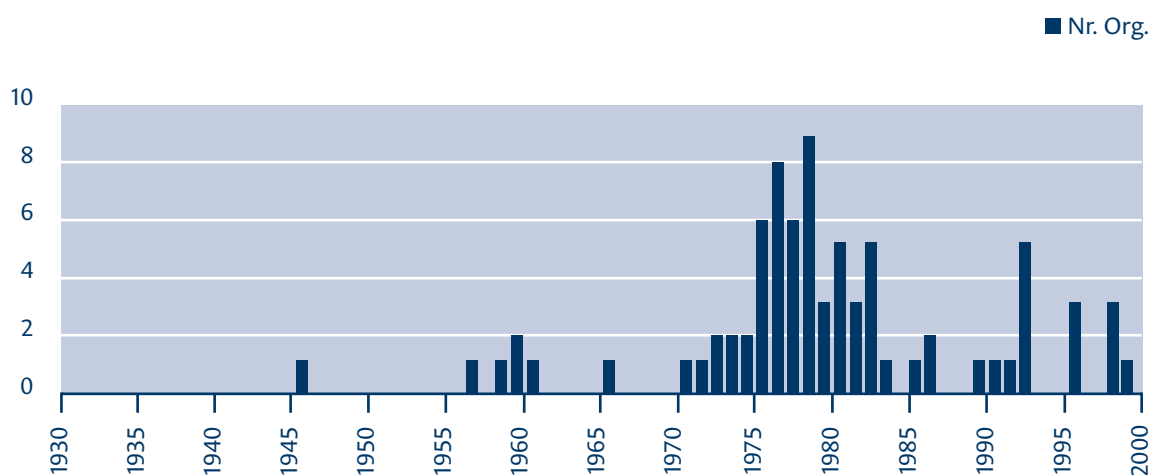
Resources and services

Along side the political and ideological development, and the development of programmes and measures, the 25th of April 1974, and the adhesion of Portugal to the, at the time, EEC, were two landmarks for transforming our reality in terms of responses and availability of resources. Without policies and programmes, in the former period, there were no resources, nor organised services. Therefore, structured networks of services only started, on one hand, with the strong associative movement of family members of people with disabilities and of other citizens, and, on the other hand, with the inception of organisations of the system, responsible for coordinating and supplying rehabilitation services.

These were later on enlarged and further pushed by the Structural Funds from the European Union, to which were added other national funds, with more of a pension nature, but with significant value.

Just as an example, and taking the sector of social and professional integration, we can say that the entities that appeared in 1974 or after are about 78% of the total amount of entities presently working in this domain. Referring not to the creation of the entities, but the date from when they started working with issues of disability, the figure reaches almost 80% (Graph 5).

GRAPH 5. STARTING DATE FOR DISABILITY ISSUES (SINCE 1930)



Note: Before 1933, there was only one institution registered (1888), the APEC from Lisbon. Source: Fichas de caracterização – CIES, 2003 (IN CAPUCHA ET AL., 2004)

Through trans-national cooperation and through the experimentation of new working methodologies, which was made possible through EC Programmes, new services, new valences, and new management and intervention strategies were created.

As a result of such legacy, presently there is a diversified set of players intervening at different levels, national, regional and local, both public, and private (CAPUCHA ET AL., 2004). The services and support which are offered have different typologies, with special emphasis in social protection, education, initial vocational training and support for accessing the labour market.

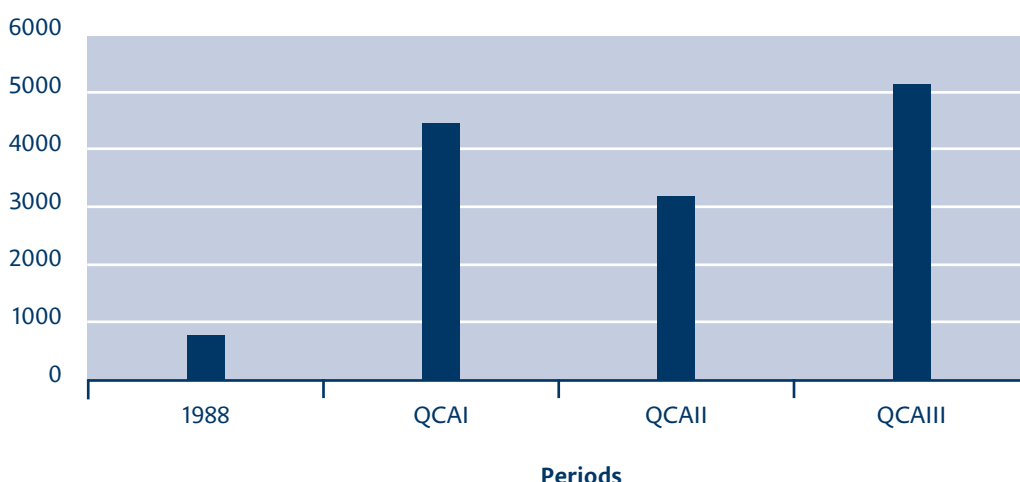
Concerns with innovation and development of services and with the adaptation of responses to the specific needs of each subject are two focal points of the rehabilitation system, progressively evolving in terms of becoming more

and more professional, which is one of its differentiating elements in face of the remaining social services. Actually, some of the innovative practices at this level were transferred onto other domains, such as education in general structures, as an evidence of the innovative elements present in the system, even though not in a general, universal way.

Persons with disabilities involved/served

This dimension of analysis also knew a similar development as the ones formerly presented. From the type of access just restricted to people with economic resources, which would allow them to access services provided by private agents, or of people in a condition of absolute marginalisation, supported in terms of bare subsistence, we moved then into a considerable and growing volume of persons that were actually recipients of services and support. Once again, this evolution seems to correlate with the funds coming from the European Union, as shown by Graph 6, presented for the cases of support granted by the Community Framework Support (CFS) within the context of social and vocational rehabilitation.

GRAPH 6. BENEFICIARIES FROM SUPPORT FROM THE CFS IN SOCIAL AND VOCATIONAL REHABILITATION (1988/02)



Note: Except for the figure for 1988, all the other are averages/year

Source: POR, 1990; DGEFP, 1995; Quatenaire/ CIES, Mid term assessment POEFDS, 2003 (IN CAPUCHA ET AL., 2004).

Access to social protection plans and the attendance of education and vocational training initiatives were the main domains of support for people with disabilities.

In face of what has been said, we may conclude that Portugal developed a set of large experiences, and that the diversity and connection of such experiences to the territories and communities, is its main added value. It presents as well some instances of innovative practices, which have even been transferred into other sectors, based on a culture of mutual learning with other partners, namely European ones. We may consider that the former decades generated a rich and enriched legacy, setting a path of effective progress at formal and instrumental levels, eventually not expressed in a proportional way in terms of results. Analysis of the data from the social characterisation formerly presented, highlights that in spite of the efforts developed in the last decades, people with disabilities are still clearly discriminated in face of the general population, which brings about the challenge of identifying the circumstances that explain that situation and of finding the paths of development to follow in order to overcome them.

A PATH TO FOLLOW

Just as examples, and without the pretension of it being a deep and exhaustive analysis of the issue, following are presented some clues of challenges, which could be considered as lines of development, emerging from the critical analysis of the former experience and that to some extent are a list of specifications for the modelling exercise, within the framework of rethinking the strategy of political action aiming at promoting equality of opportunities and non discrimination of people with disabilities. The issues-problems are presented by thematic domain and formulated as challenges to be considered, as dynamics to be implemented, to be studied in more depth.

The available knowledge on the issues

- To deepen understanding of the phenomenon of disability in Portugal, its incidence, territorial distribution and social characterisation.
- To encourage research and study on this domain, basing all decisions on empirical evidence and structured knowledge.
- To characterise of all cultural, social and economic needs of people with disabilities and of the barriers for their inclusion, as a challenge for the sector, which would then become a permanent system supplying reliable, updated and systematic information to support decision making.

- To systematise assessment of policies and practices, continuously articulating them and connecting them to the issues, instead of connecting them to the institutional dynamics from which they emanate.

Disability – concept, scope and operational delimitation

- To update, stabilise and generate consensus on all concepts associated to disability, at present still quite blurry, with little demarcation and operationalised in different ways in different policy sectors, with delimitations for eligibility not usually accurately defined and shared.
- People with disabilities are perceived as something dynamic, changeable in terms of their circumstances and condition, and not as something with a definite, well defined, and predetermined status.
- To widen the scope of the issue, evolving from disabilities, to disabilities and impairments.
- From focus on policies and interventions mainly during childhood, youth and adolescence, and in the classical typologies of impairment, congenital disabilities (namely at the level of responses and of the services supplied), to disability associated and considered along the whole course of ones life, taking into account a greater incidence upon the acquired disabilities and in the most advanced age groups.
- Relevance on prevention, considering the expression of acquired disabilities.
- Challenges brought about by aging – considered on an individual basis and as a social phenomenon – a new reality with new challenges, and requiring new responses, or a reinforcement of the existing ones, namely at the level of dependence.

Political and ideological reference

- To redirect the conceptual system towards rights, towards activation of rights and towards inclusion, at present they are still guided by the deficit model, by the medical model of disability, in terms of perspectives, formulations and practices, in spite of some openness to new conceptual models, in some regulating and guiding instruments and in some practices. At present we still see:
 - > policies and interventions focused on disabilities and on compensating their impacts;
 - > encouraging investment in searching for and proving the maximum impairment, the maximum disability, rather than investing in capacity, in reducing limitations through habilitation/rehabilitation;
 - > granting compensations independent from searching activation.

- From focusing just on people, to focusing on people within their contexts, on the dynamic interaction between those two realities.
- From just focusing and valuing impairment, to valuing and profiting from capacities, while at the same time compensating shortcomings. Policy orientation should aim at compensation, at habilitation/rehabilitation, at inclusion and at family, social and professional reintegration of people with disabilities, acquired as a consequence of diseases and accidents.
- Policies oriented not so much towards sectorial considerations by stages of ones life cycle, but rather towards an integrated and continued management of the different stages, ensuring logic of life cycle, with special focus on the transition between them.
- To develop services, at an embryonic stage of de-institutionalisation, still oriented by the logic of an assistance providing system, which generate strong institutional connections, to a strategy of complementary integration with the general community structures, the natural context of inclusion.
- Policies, programmes, measures and interventions need to be based on a common ideological framework of reference, updated and harmonised in face of the new conceptual models.
- The different sectorial policies around disability function with a logic of autonomy, whereas they should be guided towards sharing the same values and principles of reference, in a coordinated and articulated way.
- To deepen the approach of conciliation between passive compensatory measures and active inclusion measures, promoting employability and employment.
- To consider disability not just as a human problem, a problem of individuals and their families, but also and foremost as a social and political issue, and as an economic issue (for citizens, for families and for the social system).
- Development of the status of families, through policy measures of support, following their role of care takers and the relevance of their intervention.
- Policy goals for people with disabilities should tend to converge to the universal goals of general social policies.

Programmes and measures

- The present political system integrates a rather dispersed set of programmes and measures of specific nature, quite dispersed and not always coherent, at times with gaps and overlapping, and their evolution towards a global, coherent, systematic and rationalised system is quite desirable.
- Programmes and measures lack conceptual updating, in line with the new paradigms, designed in an integrated way and following the transition between the different stages of the life cycle.

- The emergence of new challenges, associated to the enlargement of the scope of policies and to aging, implies that the existing responses are reformulated and new ones are introduced in order to face these challenges.
- The transversal nature of some policy measures is not followed by a dynamics of actual and acting coordination, mobilising and binding sectorial interventions.
- Acquired disabilities, as a consequence of diseases and accidents, do not have adjusted responses, and so rehabilitation and reintegration of these people is, to some extent, dependent upon individual/family capacities and initiative, through non-structured solutions. The dominant approach in the Portuguese society has been characterised by a great deal of fatalism, by acceptance of the phenomena and of their consequences with resignation, thus generating minimalist type of interventions, very much limited to the issues of damage repair, not investing in rehabilitation and reintegration, in keeping the citizens employed and working, in their quality of life and in their full social inclusion.

Information, involvement and participation of stakeholders

- Information on rights, opportunities and resources for supporting citizens and families, in a close and accessible way, as a critical condition for knowing ones rights, for accessing them and for demanding their fulfilment is scarce, not available and not accessible in a generalised way.
- There is no counselling and orientation services, which are critical pillars for an inclusive strategy and for quality of life, with a similar status as that of other types of services, considered as fundamental social responsibilities.
- The present levels of participation of significant citizens and of other stakeholders is just limited to restricted, formal and almost symbolic dynamics.

Services and resources

- There are inequalities in access to services and resources, according to ones capacity to access information, according to ones area of residence and to ones economic and social status.
- Signalisation and assessment of the citizens' needs occur in different contexts, linked to the responsibilities of different intervening entities, and centred around institutional logics rather than on the subjects.
- The conceptual framework and technical structure of response show the need for further development at the level of empowering and technical equipments.
- In spite of the significant levels of mobilisation of general structures, very

- differently among the different policy sectors and institutional practices, segregated and institutionalised conceptions and practices still remain.
- The services network is extremely atomised, with no systemic logics, resulting from the geography of initiative, from casual decision making.
 - The services network infra-structures lack structural improvements and updating, adapting them to the legal and quality requirements, as a condition for the quality responses it should offer.

Governance

- Positioning of governmental players is based on the respective institutional logics, with insufficient articulation and coordination among them. This same dynamics is also seen at the level of representative institutions and service providers, where, besides little cooperation and articulation, there is even some competitiveness of conflicting nature.
- The sector is organised by a diverse set of principles and values, still not shared by all elements that integrate it.
- The dominant approach is a fragmented one, by policies, by organisations, by services and their delivery, according to an approach which is dimensional, fragmented by sectors, dividing the citizens into compartments, into “problematic slices”, oriented by the logics of policy administration.
- Management of the system and of the organisations is still just focused in activities and resources, in proceedings and administrative issues, with poorly structured and non systematic practices for monitoring and evaluating results and impacts from the policies, programmes, measures and interventions, and the quality of the responses which are ensured.
- The funding mechanisms are still structured in precarious and contingent terms, not usually based on the identification of needs, and for the most part include performance indicators of procedural nature.
- The rehabilitation sector integrates islands of excellence, innovative practices, with innovative dynamics but with scattered development, un-articulated, without a strategy that can frame and guide them, with little dissemination and transfer of the new conceptions, programmes and methodologies into general practices.
- There is scarce offer of specialised training for leaders and professionals in the rehabilitation sector.
- The main culture in the sector is still dominated by a philosophy of demanding, of protesting, with insufficient levels of study and proposals, with little investment in strategic and conceptual debate. In spite of the frank progress made in the sector in the last decades, Portugal has ahead of it a clear and

urgent challenge at the level of policies, programmes and interventions, in the domain of people with disabilities. The indicators of social characterisation, presented in the former chapter, point towards an obvious situation of discrimination of this social group, which in spite of not being a new nor an exclusive fact for Portugal, presents however some quite concerning contours in face of the political developments and in face of the resources that have been allocated in the last decades.

On the other hand, also at the level of adequacy of responses from the system, it seems quite obvious that there is a need for making strong adjustments in its orientation and configuration, while at the same time creating the necessary conditions for optimising response capacity, in terms of coverage and production of effects.



Chapter 7.
**Reform of rehabilitation
policies at international level**

The influence of the international context, namely of the European Union, in formulating and designing policies within the Member-States is quite visible, materialised in the types of models and paradigms which are proposed, in the definition of legal references and when sharing recommendations (GODINHO, 2007). Therefore, the design of a national strategy implies analysing the international context of reference, the international trends, with the aim of anticipating opportunities and threats, and ensuring compliance with the normative, regulatory and other guidelines. The study of national policies of other countries also enables the identification of innovative approaches and to foresee the consequences of policy measures under consideration. It is also another dimension of analysis regarding the tendencies of funding models for rehabilitation services and how they fit into the political and normative framework of the European Union, as social services of general interest.

REFERENCES

Within the international context, there are three political instruments which are the main references within the domain of policies for people with disabilities:

- the UN Convention on the Rights of Persons with Disabilities;
- the European Union Disability Strategy, from the European Commission;
- the Council of Europe Disability Action Plan 2006-2015.

In face of the relevance and transversal nature of these references, it is important to analyse and to interpret them, gathering their main guidelines.

UN Convention on the Rights of Persons with Disabilities

The Convention, adopted by the UN in December of 2006, defines a paradigm shift in terms of approach to the issue of people with disabilities. Its key message is based on the fact that all people with disabilities should fully enjoy all human rights and all fundamental freedoms. It presents a much broader spectrum than the former understanding of disability, by considering the relationship between the person and the context, in total coherence with the relational model presented in the ICF.

It is stressed that all categories of rights apply to people with disabilities and the main domains where adaptations have to be made are identified, so that they can actually exercise their rights, while also stressing the areas where protection needs to be reinforced. The Convention formulates some very specific guidelines, as well as recommendations to be considered when designing or reviewing national strategies for disabilities, of which a summary is presented below:

- To consider the structuring principles of the Convention in the national principles, namely in terms of full and active participation; respect for one's differences and acceptance of disability, as the first integrating element of human diversity; equality of opportunities; accessibility.
- To include people with disabilities in the community, as elements that actually add value, and to ban stereotypes, raising the level of awareness of general citizens.
- To see employment and employability as strategies at the service of inclusion, identifying return to work as a key dimension.
- To ensure that social disability-related services are comprehensive, multi-disciplinary and oriented towards promoting autonomy and full participation of people with disabilities.

The European Union Disability Strategy, from the European Commission

With the goal of creating equality of opportunities, this Strategy aims at creating opportunities that may allow people with disabilities to fully enjoy their right to dignity, to equal treatment, to autonomous life and to participation in society. The initiatives proposed by the EU fundament the set of economic and social values, promoting their maximum potential and ensuring their participation in society and in economic life. This Strategy is based on 3 pillars:

- Legislation and anti-discrimination measures that may enable access to individual rights.
- Elimination of barriers in the environment.
- Mainstreaming disability issues in the broader set of EU policies, in order to facilitate their active inclusion.

In 2003, the European Commission developed EU Disability Action Plan, with the purpose of making the Strategy operational. The Commission recommends that it be considered at the time of developing national policies. The Action Plan is made up of 3 stages, aiming at different key-challenges at different points in time:

- **Phase 1 (2004 – 2005)**

Focused on access to the labour market by people with disabilities, and on actions related to employability (e.g. life long learning, information technologies and accessibility in terms of physical space).

- **Phase 2 (2006 – 2007)**

To professional integration of people with disabilities, adds the focus on promoting access to high quality support and care services. After stressing the importance of accessibility of the physical space, at this stage accessibility to goods and services is given priority. De-institutionalisation and creation of services based on the community still remain as key recommendations.

- **Phase 3 (2008 – 2009)**

To be published in December of 2008, shall remain guided towards accessibility, in a broad sense, and to employment. Enforcement of the UN Convention shall be identified as a priority issue when designing policies in the Member-States. Empowerment and raising awareness within society for the topic under analysis shall be emphasised.

The Council of Europe Disability Action Plan 2006-2015, from the European Council

The purpose of this Action Plan (COUNCIL OF EUROPE, 2006) is to offer a holistic, flexible and adaptable framework, in order to correspond to the specificities of each country. It clearly presents itself as a reference for political decision makers, in order to support them when designing/reviewing and implementing innovative plans, programmes and strategies. It contains fifteen lines of action, namely focused on participation in domains such as political, public and cultural life, equal access to education, accessibility to all built patrimony and means of transportation, life in the community, rehabilitation, social and legal protection, research and development, and raising disability awareness.

The Action Plan also highlights the phenomena of multiple barriers and of double discrimination, emphasising that certain groups are specially affected by greater risk of exclusion, namely females, persons in need of much specialised support, children and youngsters, elderly persons, and people with disabilities from minority and migrant groups. These specific groups require a transversal and intersected type of response, with other action domains, in order to insure their inclusion in society.

As references, these political instruments enable the identification of some of the main guidelines from the international context. From these and from the experiences from other countries, especially from the European Union, we can identify some development trends and lines for reforming rehabilitation policies, with special focus on the impacts that shall follow from that, when designing strategies, programmes and interventions related to disability.

DEVELOPMENT TRENDS

Holistic approach to disability

As disabilities are considered a complex phenomenon, made up by different elements, and in which different variables interfere, it is assumed that intervention policies and practices that respond to them should also be comprehensive, integral and integrated, using references which consider the different dimensions of the individuals' lives. In this way, identified individual needs should find an answer in multiple policy domains and/or in multi-disciplinary interventions.

This concept implies the identification of coordination strategies for transversal measures and mechanisms in the various political domains that interfere with the topic under analysis, namely, health, social welfare, employment, education, transportation, sports and leisure. The type of thought divided into silos (ministries, departments, thematic domains) is actually one of the main barriers to this approach. The role that funding may take should also be stressed, in terms of de/fragmentation, according to the options that have been made, for supplying holistic services, as they aim at responding to an issue that is also holistic in itself.

Different strategies and processes may be implemented in order to ensure coordination of a continuum of services supplied to people with disabilities. Creation of a governmental structure responsible for all working dimensions related to disability, of a transversal and integrated national strategy, coordinated by a government agency, or of a multi-sectorial approach, based on a set of common goals and criteria, are the main examples. Countries such as Germany and Sweden have already legislated in order to guarantee a wide set of disability-related services, for all people with disabilities (OECD, 2003). In terms of implementation, some countries chose to set up one-stop shops, for providing information services, counselling and trans-sectorial advocacy. Others have introduced case management services with the purpose of supporting access to all services identified as necessary at an individual level.

Independently of the strategy or combination of strategies which may be adopted, it is fundamental to ensure two critical factors: individualisation of intervention plans, and the establishment of partnerships among the different service providers and the key players in the community.

Provision of holistic services is also advocated, starting with global assessment of the individual's needs and then materialised in individual plans, assumed as the privileged mechanism for ensuring a significant integration of the different services into the personal narrative of the individual. As far as the individual plans, it is important to consider some critical elements:

- To ensure independence between the assessing unit and the service provision unit, at the risk of the client being affected by conflicts of interest (e.g. focusing on supply management, rather than on orientation towards the client).
- To provide support in the implementation of the individual plan, in terms of access to services, sharing of information and cooperation in the analysis thereof, in order to enable informed decision making.
- To avoid that the individual plan becomes an administrative procedure, which main concern is to comply with legal procedures, putting aside the actual satisfaction of the actual needs of the client.

Activation model

Option for a political model oriented towards activation, present in the different European documents of reference, is related with the present concern of reconciling economic growth and prosperity with social cohesion, leaving aside the model based on redistribution of income and in compensatory allowances.

It is based on stimulation and activation of individuals, in a logic of promoting their autonomy, granting greater responsibility and greater control to people with disabilities. Intrinsically associated to employment promoting policies, this model enables to move from a tax consuming paradigm to a situation of tax payer. Therefore, it promotes the generalised perception that expenditures with social disability-related services, aiming at the whole rehabilitation of the individual, fomenting their autonomy and supporting their professional integration, are not expenses, they are rather an investment with social and economic return.

Early intervention

There are many positive impacts associated to implementing the principle of early intervention (e.g. minimisation of impacts from changing structures and functions; reduced risk of pension dependence). It supposes the immediate performance of an individual needs assessment and the implementation of the rehabilitation process immediately after the disability was identified or acquired.

It should be highlighted that early intervention refers to, not just the first years of ones life cycle, but also to later stages, such as intervention at the time a professional disease emerges. Actually, a present concern is the fact that the main addressees of early intervention, especially in cases related to the labour world, are not compatible with the present eligibility criteria established for disability-related services. In other words, only when the condition of these persons reaches more serious degrees do they become eligible for such services, which translate into increased personal, family, professional, economic and social costs.

Importance of employment as the key-factor for social inclusion

Not disregarding the fact that individuals are considered as single and indivisible beings, to which any intervention should be comprehensive, the importance of professional integration is considered with special emphasis in several European policies referential systems. Considered as a fundamental element for social inclusion, for economic independence, and for personal fulfilment, several countries have assumed the need of fomenting integration of people with disabilities in the regular labour market. In order to achieve that, the following elements take up relevant roles: quality vocational training, which is homologated and provides certificates; supported employment and disability management services; prevention of diseases and labour accidents; supporting job maintenance and return to work, of all workers victimised by any disease or accident; managing disability in the work contexts, not in a reactive way nor in the context of social protection.

At this level, we may summarise some recommendations from European surveys that enquired employers and service suppliers from different countries (OECD, 2003; OPTI-WORK CONSORTIUM, 2007):

- Importance of ensuring that the policies which are designed do actually advocate equal treatment in the regular labour market.
- To develop information and awareness campaigns.
- To provide financial support to employing entities.
- To create a climate of stability, ensuring that support is unaffected by Government changes.
- To design policies that avoids undesired side effects (e.g. less opportunities of professional integration for people with disabilities caused by the legal difficulty of dismissing them, in face of the remaining population; maintenance of pension dependence, due to the difficulty in accessing such pensions after an experience of professional integration).

Ageing

Increased average life expectancy, both in general population, and in people with disabilities in particular, brings about some challenges when designing and implementing policies and practices. Population ageing generates an increased number of persons with disabilities, following from changes in structures and/or functions due to age. Cumulatively with more extended lives of persons with disabilities, there is also an increased number of persons in need of support services, as the usual responses in terms of care, provided by parents or other relatives end, or because they do not survive them, or because they themselves acquire disabilities as a consequence of age.

In this way, it is generally accepted that there is a need to move from a model of care provided within the family, to a model of care provided by professionals. Besides the increased demand for continued support services, aging brings additional challenges to policy agents and to stakeholders related to disability, namely to service providing organisations, such as the need to conceive different strategies and methodologies that may respond to the needs of elder addressees.

In order to timely prepare appropriate services to the above mentioned challenges, three strategies may be identified:

- To keep people with disabilities in the services where they already are, adapting them to their needs, anticipating the possibility of obstacles, such as the un-reasonability of making changes to certain buildings, or resistance to more radical changes by other clients.
- Development of new specialised services for elder persons with disabilities, which implies a high degree of competence and specialisation, training of professionals and resort to other sources of funds.
- Mobilisation of elder persons with disabilities for regular services that respond to issues related to aging, where they can socialise with other persons of the same age group. This option has a positive binomial cost/effectiveness. However, it implies the risk of the service being inadequate for people with disabilities and of these persons being ignored by other clients.

Independently of the strategic options that are made, international experiences, in line with the reference systems of the policies in force, stress the importance of developing legislation and measures that may anticipate support to decision making, whenever people, due to their disability, show great difficulty in the decision making processes.

International Classification of Functionality, Disability and Health

As already addressed in earlier chapters, the ICF is generally accepted, in the international context, as the conceptual basis for formulating definitions, policies and measures related to disabilities. So, the relevance of ensuring coherence between this classification and the methodologies and instruments for data collection on the functional condition of the population is stressed, as this knowledge, if valid and reliable, is a fundamental element for programming policies. This principle of conceptual alignment also applies to legislative and normative reference systems.

Mainstreaming

Mainstreaming, as an expression of equality of treatment, advocates that the topic of disabilities should be incorporated into all policies, programmes and

actions, from where some political and intervention challenges naturally follow. Assuming the need for social services related to disabilities, with the aim of meeting needs that call for highly specialised responses, one of the first political challenges is to prepare regular services for the integration of people with disabilities and to convert special services that still remain. Considering the needs of the former and the know-how and experience of the latter, one of the approaches is based on transforming the latter into consultants for regular services. Independently of the option that is made, it shall always imply a change of strategy and of organisational structure, and a change in the approach of intervention.

One of the measures oriented towards mainstreaming has to do with creating anti-discriminatory legislation, where there already is a consolidated European past, expressed by the European Directive against discrimination. So, it is required that each country ensures its compliance and eliminates physical, psychological and social barriers that still make it difficult or impossible to fully integrate individuals in the regular contexts.

Community-based rehabilitation services

This type of approach integrated in community development and based in common principles with mainstreaming, refers to promoting equality of opportunities and social inclusion for people with disabilities within the context of their own communities. It is implemented through harmonised actions including people with disabilities, their families, associations and governmental and non-governmental agencies, related to service provision in domains such as health and education. This European recommendation aims at activating communities, in order to promote and to ensure respect for the human rights of people with disabilities, by introducing changes in the community itself, such as eliminating barriers to participation.

Although and often the actions are initiated by Ministries or non-governmental organisations, civil society is drawn in for active participation, and the responsibility is given to the community itself. Present experiences allow us to identify some critical factors in order for this approach to be successful:

- It is fundamental that national policy is assumed as the guiding reference system, establishing general priorities and planning the programme for Community-based rehabilitation services.
- Coordination must be ensured at national level, and appropriate resources must be allocated.
- Trans-sectorial collaboration is required, in order to ensure the adoption of a holistic approach.
- Establishment of partnerships among key-players.

Client involvement

Client orientation and the creation of opportunities for promoting client participation in policy and programme design, monitoring and evaluation, are advocated by several international policy systems of reference. Therefore, representation of people with disabilities at governmental level and in all frameworks for policy action that may involve the topic under analysis must be ensured.

Client involvement integrates the ethical dimension of the motto “Nothing about us, without us”, from the European Year of People with Disabilities (2003), connected to an entrepreneurial rational, based on seeing “users” as clients, with rights and obligations, based on contracting services and co-accountability.

Within the framework of optimising client participation in the development of strategies and management of structures for service providers, clients assume themselves as key partners in the provision of disability-related services, as in any other management strategy. It should be highlighted that in order to ensure full and effective client involvement and participation, it implies that they must have access to information and that they may interpret and analyse it, in order to be able to take up their role as policy decision makers or counsellors.

In close connection with this dimension, some strategies have been initiated such as granting personal budgets or making direct payments, which enable that the *locus* of control becomes situated in the persons with disabilities, as well as promoting their empowerment, as it enables them to access the services they desire, wherever and whenever they want.

It is also seen that there is an international tendency for introducing a culture of co-accountability. Therefore, along side the State’s responsibility, in what concerns promoting initiatives for supporting people with disabilities and fomenting their social inclusion, which is, in general, assumed *a priori*, there is the responsibilities of the own persons with disabilities and of key social players (*e.g.* employers) within the scope of policies and interventions. In this sense, in several countries, the legal and institutional structures are starting to be rethought, and initiatives to transform norms and values are starting to be implemented. One of the strategies that has been adopted refers to the establishment of participation in support measures for inclusion as a criterion for accessing social allowances. Participation in rehabilitation programmes is already mandatory in several countries (*e.g.* Austria, Denmark, Spain, and Sweden). It should also be mentioned that, in most cases, this obligation is managed with flexibility, considering certain aspects such as the age or professional experience of the person at stake (OECD, 2003). On the employers’ side, several strategies are implemented, such as assigning the legal responsibility to the employer for the adaptation of the workstation or identification of another function within the same area (IBIDEM).

Service quality and modernisation

As a consequence of the growing focus on the relationship cost-efficiency, of the appearance of competitiveness among service providing organisations, of the trans-national dimension of services and, above all, as a question of rights, the issue of quality of the services provided has taken up greater and greater visibility and pertinence. Identified by the EU as a key-area in the domain of social inclusion, it is found in several European reference systems, with special relevance in the 2nd stage of the European Action Plan.

The tendency for the rehabilitation services market to become more and more European, connected to the emerging forms of funding, shall enable individuals to benefit from services in other countries, professionals shall be able to move within the European context, and service providing organisations may conquer international territories.

Therefore, it is necessary to ensure quality services to both clients and funding agents, as well as to equip service providing organisations with an instrument that may enable them to give evidence of their competitive advantage. The present tendency, points towards the response to these needs being provided by formalising a European quality reference system, based on the total quality management approach, and materialised by values and principles of excellence. As the responsibility for regulating services provided to people with disabilities is up to each Member-State, the reference system shall necessarily be flexible, in order to be able to adjust to the own idiosyncrasies of each country.

This line of reform implies that enforcement of the ruling principles of social service is assured (ASSEMBLY OF EUROPEAN REGIONS COMMITTEE B, 2005), namely in what concerns accessibility, economic accessibility, availability, continuity, quality and transparency. Qualification of the rehabilitation staff is also considered as a fundamental aspect of service quality and modernisation.

Such modernisation implies a paradigm shift, expressed by giving up the logics of assistance type of system and by adopting a philosophy based on rights. From here, follows the need to review the vision, mission and structure of service providing organisations. It implies as well the use of more entrepreneurial management models, oriented towards results, while not neglecting the social nature of the activities developed.

To demonstrate the value of services

In the last years, in the European context, service providing organisations related to disability have been pressured to demonstrate the value they actually add, both according to an individual perspective (value produced for their clients),

and according to a social perspective. Shortage of economic resources, overloaded social welfare systems, increased number of persons in needs of services and greater expressions of citizenship by individuals, are some of the causes associated to such pressure.

In order to demonstrate and give evidence of the value added by services, different strategies may be implemented, while the adoption of a multiple strategy is seen as the most effective:

- Orientation towards result assessment, focusing on the impacts caused to people with disabilities, to their families and/or to other significant others and to society – result evaluation of services, in economic (e.g. number of persons with disabilities integrated in the labour market) or social terms (e.g. levels of social participation).
- To compare cost-benefit analysis between services provided in relation to disabilities and other alternative options, including no response, as a strategy to demonstrate that rehabilitation may not really be an expense, but rather an investment.
- To consider efficiency, besides just effectiveness, through appropriate resource management.
- Emphasis on service quality.

FUNDING REHABILITATION SERVICES

The European social model, consolidated between the 1950s and 1980s, started a decisive period from the decade of 1980, while presently going through some dilemmas at the level of its pillars and its strategy:

- The need for new strategies that may favour economic growth and prosperity, instead of focusing on re-distribution of income and granting pensions;
- The emphasis on the individuals' obligations towards society, and not just on their rights and claims against society;
- To favour support to specific and vulnerable target groups, and to not advocate horizontal redistribution of wealth;
- An important way to support these changes shall be through increased competition and service privatisation, rather than just public provision of services.

Within the context of these changes and of the associated dilemmas, following we identify and systematise some of the main tendencies, found in the international context, as far as the evolution of rehabilitation services and of the funding models, while analysing as well, the advantages and disadvantages offered by the different models and the requirements for their implementation.

Growing tendency for decreasing public and national approaches, and to increase the role of regional and local communities

The strategy of increasing the level of responsibility of regional and local communities for services provided to people with disabilities, and for the respective funding, has been steadily growing. The fact that entities are situated at a level of greater proximity, such as the region or local community, presents several advantages. It enables a better knowledge of people, facilitating the understanding of their problems and improving the understanding of their real needs, as well as to award responsibilities to all of those involved (inclusively to the persons with disabilities themselves).

However, implementation of lines of reform going in this direction also meets difficulties. The service being provided may be influenced by the community itself, and by the existing financial resources at regional or local level. This means that two citizens with disabilities, with similar activity limitations or similar participation restrictions, may not get the same services in two different regional or local communities. Just because significant differences may exist in terms of wealth between them or differences in terms of policy models or practices which were adopted – more of assistance nature in one community, or more oriented towards promoting independent life and autonomy, in the other one.

As a consequence, and according to the principle of equality of rights, opportunities and condition, increased importance of the roles of regions and local communities in solving problems of people with disabilities should not take away the responsibility of Central Administration, both in terms of defining the main policy lines, and in providing the closer instances with funds and other necessary resources, as well as in monitoring enforcement of the principles of national policy.

Growing trend for transferring service funding and execution, to private organisations

With just some exceptions, this tendency may be observed in most European countries. Moving service funding and execution to the private sector may bring some advantages. On one hand, it is assumed that private companies, competing in the open market may provide services at much lower prices than the public sector. On the other hand, it is easier to link the services which are offered to the funds which were obtained (funding model indexed to results), as transparency of the market tends to increase with competition.

In the same way it is considered that flexibility of the organisations, and the services they offer shall tend to increase, since private companies tend to re-

spond more swiftly to changes in the market than public organisations. In the service market of the 21st Century, there will be much more orientation from the demand side than in the past and it is assumed that, in principle, private companies may more easily implement new ideas, new services and respond more swiftly to new demands.

However, recent experiences show that there are some issues with private service provision. Within market logic, the quality of services being provided is influenced by the price defined by the organisations. Within an open and competitive market, ultimately the price shall always determine who shall sign the contract (in other words, the offer at the lowest price wins) or who shall win the public tender. And this may mean, not just that quality of services may be negatively affected, but also that services which imply greater profit for the company shall always be the chosen ones and the ones to be offered.

However, criteria for funding services to be supplied by the private sector may not just be based upon prices, but also include other variables, such as the activities to be developed or the results obtained (e.g. number of clients placed in the labour market). However, even in these cases, it may still not prevent that there is a new selection of clients and of services to be offered, maintaining the tendency of organisations from the private sector to choose those that potentially yield better results for those variables, which requires appropriate training in contracting, in lists of specifications and in contract regulations, ensuring the principle of universal right to access quality services.

Growing trend for decreasing public funding and to increase co-participation by users

Service funding through co-participation or co-payment by users are important regulators and contribute to less public funding. It is rather positive that, before requesting services considered as necessary and before requesting the respective public funding, all stakeholders – providers and people with disabilities – think over the contribution they have to render. Such prior assessment contributes to raise social accountability of all players, to valorise services provided, and to their rational use. In general, co-participation is defined on the basis of income *per capita*.

Obviously, an issue still remains, which is to know who shall ensure funding of services to be provided to persons that can not take part, either fully or partially, in the price to be paid. Naturally it is accepted that it is the responsibility of public funding to ensure the indispensable services with an appropriate level of quality. Besides, it is expected that there will be permanent pressure for public funds, and so, as people become older, and in many cases, as people lose income, they try to decrease their share in co-funding.

Growing trend for involvement and individual accountability of persons with disabilities through the means of personal budgets

Within the framework of decreasing the role of the State and of holding the persons themselves accountable, there is a growing tendency towards the empowerment of people with disabilities, through a strategy of providing them with funds which allow them to acquire the services they need. This tendency applies to all sorts of services provided and to all sorts of groups of people: youngsters with disabilities, students, professional re-integration or continued care.

Personal budgets are granted with the purpose of increasing people's power of decision upon the quantity and quality of services they actually need. The amount of funds depends on the service required and is influenced by the degree of seriousness of the impairment. In some countries, there is a special committee to decide on the amount of budget to give to each person with disabilities.

The specific goal defined for the personal budget determines which is going to be the funding entity. In case the purpose of the budget is to acquire additional health care or education, it may be directly funded by the State budget. In the case of a budget related to work and employment, it may be funded by the Social Welfare Department. In some cases, the personal budget is connected to the development of a Personal Plan of Re-integration – for instance, a plan that details the way that a specific person intends to define his/her return to the labour market. In case the plan is accepted by the decision making instance, the person receives vouchers in order to hire a re-integration company that may provide the services the person requires. In turn, the re-integration company that has been hired receives funds on the basis of the results that have been achieved.

Therefore, a personal budget is a funding model used in social policies, not just to increase accountability and empowerment of people with disabilities, but also to achieve a certain response which involves shifting to client centred approaches, instead of service centred approaches. It is not a solution to solve all problems of people with disabilities, as they have to be able to choose from different services, to understand their own needs and to translate them into services and into their respective prices. Actually, the personal budget requires a great deal of reflection on one's personal condition and on each individual's needs.

As a matter of fact, there are some minimal conditions for implementing direct payments. By choosing the mode of direct payment, the person should have the right to receive training that may prepare him/her for managing such funds. And those that do not at all possess the necessary capacity for such fund management should benefit from services provided by a professional in order to fulfil such role in the person's representation. It is also necessary to have several service providers in the same region, so that there is competition and the opportunity for making choices, as well as that the interested parties resort to such

service providers, which does not always happen spontaneously, often people prefer to remain under the dependence of pensions.

Personal budgets are an appropriate solution in some cases, but for all those with limitations in decision capacities, they may not be appropriate to the extent that the persons are not able to acquire the services they require.

Therefore, the effectiveness of the model of direct funding and of personal budgets depends quite significantly on the way it is implemented.

Growing trend for paying special attention to funding during transition stages

During transitions between different life cycle stages and between changes in the situation of persons with disabilities, funding of services is generally more problematic. Responsibility for the different stages does not report to the person, but to different legal frameworks aimed at different groups, and to different funds for different services. In general, funding during the first stage of life is predominantly ensured by the Ministries of Health and Education and during active life by the Ministries of Labour, Employment, Social Affairs, Health or Social Welfare. It can also come from a combination of these departments or come from private insurances. After active life, or when continued care is required, funding may be done through private insurances, through Social Welfare or Health Departments.

From here result dispersed responsibilities, dispersed legal frameworks, dispersed criteria and dispersed granting mechanisms, which easily lead to situations in which people lose the support they had the right to at a given stage, without guaranteeing the corresponding support in the stage they moved to, if there is no effective coordination. Thus, coordination of interventions is most essential.

Growing trend for funding indexed to results

Concerns with fund management by funding entities have been increasing, making them depend on the results achieved. The countries of the Organisation for Economic Cooperation and Development (OECD) spend significant amounts with their programmes for supporting disability. Often, persons that enter into these programmes remain until the end of their active life, when, in reality they seem capable and actually wish to actively participate in society, if an opportunity, training and the necessary support are given to them.

So, policies have to emphasise results, namely in terms of development of employability and of employment of people with disabilities, they have to review the system of benefits so that they move from a logic of assistentialism

to a logic of activation, and they have to make all stakeholders accountable for achieving those results.

Indexing funding to results supposes that assessment criteria and assessment indicators are defined. However, it is necessary that this criteria and indicators be established in such a way that achievement of results does not encourage selection of groups of people with disabilities, excluding the most difficult cases.

Growing trend for advocating a culture of mutual obligations

Granting funds to rehabilitation services tends to be conditioned by participation of people with disabilities in the programmes and measures that were planned, according to a contracting logic. This is what happens, for instance, with the support programmes for integration in the labour market, in which people take up the obligation of actually participating in orientation and training initiatives, and in other integration measures. Active participation tends to become a counterpart of the funding which was received, while sanctions are applied in case of non compliance. Naturally sanctions shall not take place in those situations in which no integration strategy seemed possible.

Employers, also have their obligations, which vary according to the different countries, from legal imposition of job quotas to be made available for people with disabilities, to defining different and appropriate tasks to the different types of workers, to carry out training initiatives, and to making the necessary changes in the working environment, generally with the purpose of being able to keep the jobs of workers that suffered labour accidents or that contracted professional diseases.

Such logics of mutual obligations, following from funding which was granted, also implies that progress is made in the sense of defining clear and transparent eligibility criteria for fund granting.

POLITICAL AND LEGAL FRAMEWORK OF SOCIAL SERVICES OF GENERAL INTEREST

Promotion of social progress and achievement of a high level of employment are some of the main goals of the EU. Achievement of these goals is structured around a large array of social services to be provided in each Member-State.

According to the principle of pension, which rules the intervening role of the EU, in principle, definition and organisation of social services is a responsibility of the Member-States, at national, regional and/or local level, or also transfer

thereof to social partners, depending on the rules for delegation of competencies in force in each Member-State.

Even though the specific competencies of the European Commission, both in the fields of social solidarity and health has been significantly limited, and even though the EC only has either shared or support competencies, however the influence of its legislation has been growing significantly, namely in an indirect way, through the implementation of EU rules on the internal market and on competition.

In order to better explain the scope of action of the internal market rules, it is important to identify the different **types of services** integrated therein, according to the activities provided.

- **Market services**

Industrial products without any intention of providing public service.

- **Services of general interest**

They ensure daily needs of people and are vital for their well-being. Quality of life of the citizens depends on these services, which are essential for sustainable economic development and for social cohesion in Europe. Electricity, mail services, transportation, and social and health services are some examples of such services. Their main goals are the same: to implement social and economic rights of people and to achieve economic, social and territorial cohesion. In the achievement of such goals, quality of the services provided takes up a very important role. Services of general interest should be based on the following principles of quality: equality, accessibility, economic accessibility, safety and security, proximity, continuity, transparency, universality and participation. Here, the economic activities – developed by companies within a given market – and the non-economic activities – performance of a non-profitable public function – would be integrated.

- **Social services of general interest**

Services of general interest for the whole population, aiming at operationalising goals or objectives of social policies (e.g. support from social welfare and provision of health and rehabilitation services). They are based on a complex interaction between services providers and their clients, often in situations of vulnerability and in situation of dependence. They are focused on the rights and needs of citizens, so, endowed with a holistic approach, both in terms of formulation, and implementation. Establishment of a relationship of trust between the service provider and the client becomes especially relevant. These services may be considered as economic activity, or as non-economic activity.

The relevance of distinguishing between economic activities and non-economic activities is based on the fact that the latter are not subject to certain rules, such as competition rules, as state support and as public funding.

From the types of services above enumerated, we may conclude that the existence of certain aspects such as solidarity, achievement of social goals, or non-profitable nature of the entity, does not exclude that the activity being developed may be considered as an economic activity, understood as an activity consisting in the offer of goods or services at a given market.

In cases in which only some activities provided by a given entity have economic nature, only such activities shall be ruled by principles of economic activities. Besides this, to create a list of activities that may be identified, *a priori*, as economic activities, does not seem possible. The concept of economic activity is a developing concept, partially influenced by the political options of each Member-State. For instance, a given State may decide to transfer certain tasks, generally under its responsibility, onto a company. Member-States may also create the necessary conditions to ensure the existence of market for a certain product or service which, otherwise, would not exist. From this intervention from the State, a certain consideration would then result, of the activities at stake having an economic nature, and so, of falling within the scope of the rules of competition and of the internal market.

Specificities of social and health services of general interest

Within the scope of the EU legislation, social services are not a legally distinct category, within the set of services of general interest. However, the specificity of social services in relation to others services of general interest was already stressed by the Commission, based on the following characteristics of social services: 1) they operate on the basis of the principle of solidarity; 2) they are comprehensive and personalised; 3) most of the time they have non-profit nature.

However, and just as examples, we may mention some resolutions from the European Court of Justice, in which, in terms of vocational rehabilitation, support services for getting a job, and in the field of housing, support for acquiring or renting a house, have all been considered as economic activities.

Application of market rules to social and health services

When approached as having an economic nature, social services are under the rules of the internal market regarding free circulation and free service provision. Recently, a Directive related to services in the internal market was adopted (commonly known as the Bolkenstein Directive), with the purpose of clearing any barriers to the entrance of other service providers in the market, and to free circulation of services between Member-States, thus increasing competition.

This directive received several interpretations, and was understood, in some cases, as an attempt to privatise services and, in other cases, as a risk factor for the European Social Model. After the position taken up by the social service sector, social services and health were not included in the scope of action of this directive. However, they still follow the principle of the internal market, which created a situation of legal uncertainty, both for service providers, and for clients.

In terms of granting public funds to social and health services, as mentioned above, Member-States may directly provide the services or else transfer such responsibility to other organisations. In either case, the rules of public funding are applied. The principles of equal treatment, mutual recognition, proportionality and transparency are all respected.

In this way, an appropriate degree of advertising should be ensured in order to guarantee that all potential interested parties may tender, and the conditions and criteria should be objective and applied in a transparent and non discriminatory way. Governmental instances may opt for the proposal with least costs, or for the proposal which has more economic advantages. In the latter case, the application documents should contain all the assessment criteria and respective weights.

It is foreseen that this situation is going to generate greater competition among service providers and that it is going to create the need for defining instruments for quality verification at EU level. Thus, procedures for EU certification and quality standards shall be developed. Following from that, there will be more pressure to give evidence of the added value of services provided by each entity, as well as a greater focus in trans-national cooperation.



Chapter 8.
**A policy model for enhancing
quality of life**

As a consequence of the progress made in the last decades, as described in Chapter 6, Portugal presently has a set of national policies, programmes and plans, with direct or indirect incidence upon people with disabilities, out of which we would highlight the Action Plan for Integrating People with Disabilities (PAIPDI). It also has the advantage of a constellation of initiatives, mostly local and solidarity ones, aimed at this segment of the population, an architecture of intervention and response, with very high potential, even if lacking some development and optimisation. At the level of financial resources, besides national resources that have been allocated, the Operational Human Potential Programme, within the scope of the Strategic National Reference Framework (QREN), shall keep assuring funds for this specific area, in line with what has been happening since 1987, when Portugal joined the European Economic Community.

In line with the above mentioned progress, and with the acknowledgement that the human and social condition of people with disabilities still places some tremendous challenges, which require ambitious and bold measures and options in order to solve the existing problems, it is fundamental to create a model with a vision and political strategy, with an approach in terms of development and progress, based on the passed but determined and oriented towards the future.

The model presented herein has no intention of replacing or criticising the present strategy and dynamics. On the contrary, it is actually based on the experiences and on the path walked over the last decades and in what is projected for the coming years, in order to argue that the country has already reached a platform of development of its policies in this area, and so now it can design a more ambitious long term strategy in order to achieve structural transformations in the situation and living conditions of people with disabilities.

One may argue that long term models tend to project utopian objectives, because of being overly ambitious, and that such ambition may negatively affect practical actions carried out at each point in time and which are actually producing effects. Firstly, that is not at all the approach adopted herein, and, on the contrary, this proposal implies an articulation between the long term strategy and the short and medium term policies, through the means of global and sectorial action plans. Using an image, the results of the long term strategy shall be like the top of a mountain one wants to reach, and the short and medium term actions shall be the steps of a walk which shall produce better results if they are pointed towards the most effective way of reaching the goal. In this work, we understand long term as the horizon of a generation, the amount of time required in order to plan and to act in a harmonised way to achieve results that imply structural changes.

Thus, we came to a conceptual model which can be applied to a Portuguese strategy for people with disabilities for the period until 2025. The choice for such a time period is not original of this work. Already in 2005, the United Kingdom

Government adopted a strategic plan, named *Improving the life chances of disabled people* (cf. GOVERNMENT OF UNITED KINGDOM, PRIME MINISTER'S STRATEGY UNIT, 2005) which had a similar time period.

MODEL STRUCTURE

The strategy model is based on the principle that any policy for citizens with disabilities aims at maintaining people's optimum levels of autonomy (Nijhuis, 2006) and corresponds "to mobilising multidisciplinary, coordinated and customised support and interventions, aiming at solving specific contextual challenges of the client, development of personal competencies and mobilisation of resources, in order to maximise levels of activity and to promote participation in the community".

Now, how to contribute towards the greatest possible autonomy of people with disabilities? As expounded in Chapter 3, since quite some time a holistic approach to disability has been developing, focused on people and reflected in operationalising the concept of quality of life ⁽¹⁵⁾, in all policies in this domain.

The concept of quality of life is quite appropriate for defining policies for citizens with disabilities, for the same reason it is quite appropriate for policies aimed at the well-being of citizens in general, as it addresses human needs and sees the human being in his/her full realisation, as the result of an approach to the different domains in which his/her well-being and life in general are played.

For the purpose of making the concept operational, in the definition of the strategy presented herein, below we define a set of key dimensions of quality of life ⁽¹⁶⁾, named as domains of quality of life, and grouped into three areas of quality of life (Table 42).

(15) *The concept itself was developed in the field of policies for mental disabilities, specifically by Schalock, and in the field of health, by the World Health Organisation. But there is also an extensive use of the concept by sustainable development policies, and by local policies, in several countries.*

(16) *This definition specifically owes to the contributions of Schalock, (1996); of the WHO, (1995) and of Costanza et al., (2006)*

TABLE 42. DOMAINS AND AREAS OF QUALITY OF LIFE

Areas of quality of life			
	Physical and material well-being	Self determination and personal development	Rights and social inclusion
Domains of quality of life	Income and social allowances	Autonomy and resilience	Acceptance and respect
	Health care	Accessibility in terms of programmes and communication	Legal protection
	Work and employment	Psychological and social competences development	Performance of roles and functions in public life
	Housing	Life long education and training	Solidarity
	Tourism and leisure	Creativity and emotional expression	Integration in social networks
	Mobility		Family
			Activation of rights

The first area has to do with *physical and material well-being* and it gathers a substantial amount of aspects that have been the focus of rehabilitation policies: satisfaction of safety/security and subsistence needs (income and social allowances, health, housing), extension of freedom and participation levels (mobility and housing), to which the domain of leisure is added (tourism and leisure).

The second one has to do with *self-determination and personal development*, and it includes satisfaction of participation needs, through the development of personal competencies (life long education and training, and psychological and social competences development), areas to which policies and institutions have also given some emphasis. Other areas, which have systematically been less analysed, such as self determination of persons with disabilities are added (autonomy and resilience, accessibility in terms of communications and programmes, creativity and emotional expression).

Finally, an autonomous area is created related to participation in collective life, named *rights and social inclusion* which gathers domains connected to civil and political rights of these citizens (acceptance and respect, legal protection, activation of rights, performance of roles and functions in public life), and con-

nected with their participation in collective life in general (family, including creation of their own family, solidarity and integration in social networks).

Each citizen has a certain level of fulfilment in each of these areas of quality of life, corresponding to his/her amount of quality of life. This has a subjective or inner dimension (the perception the citizen has of his/her own quality of life) as well as an objective or exterior dimension (the measurable differences of statistical indicators and the differences between this citizen and citizens in general), which often do not coincide. Ultimately, an alienated citizen may feel completely satisfied (have total subjective well-being) while being in a condition of total exclusion from the levels of well-being of the society in which he/she participates (have total objective exclusion). In the opposite extreme, a radically unsatisfied citizen may find himself/herself in the opposite condition.

So, policies for enhancing the quality of life have to be directed, i.e. have to aim at improving the potential of quality of life of each citizen, in terms of both dimensions: the dimension of subjective well-being, as well as overcoming the difference between the quality of life of that specific citizen and that which he/she could achieve in the society where he/she is living, independently of the perception he/she has of the phenomenon.

According to this conception, the strategy to be adopted should be centred on the action for increasing the amount of quality of life, and it has three main axels of action:

- creation of opportunities: to increase the opportunities that social collectivities and institutions create for citizens with disabilities;
- development of competencies: to act along with people with disabilities so that they may improve their “conceptual equipments”, i.e. their conditions for personal development and social participation;
- change of standards and values: to transform the perception that citizens with disabilities have of their own condition and the perception that social collectivities and institutions have of that condition.

Understood in this way, this strategy is transversal to all domains of quality of life and is centred on the citizen, instead of trying to improve each “slice” of intervention or to add new “slices” to those that have been developed so far, according to the traditional administrative logics. Here lies one of the main pillars of a policy model and strategy, thus appealing to a movement to de-stabilise the traditional positioning of policy segments, to a certain “Copernican revolution”, moving away from being focused on the logics of the Administration, to the logics of the citizens.

The importance that each domain of quality of life should have in the strategy proposed, crossing it with the types of actions for enhancing the quality of life, was identified by a group of experts and institutional representatives of the sector, within the scope of an activity in which the following question was addressed to them: “What relevance should it have in a future rehabilitation strategy?” (Table 43).

TABLE 43. RELEVANCE FOR A FUTURE STRATEGY IN EACH DOMAIN OF QUALITY OF LIFE, ACCORDING TO THE TYPE OF ACTION FOR ENHANCING THE QUALITY OF LIFE

Domains of quality of life		Strategy of action		
		Creation of opportunities	Development of competencies	Transformation of standards and values
Physical and material well-being	Income and social allowances	●	●	●
	Health care	●	●	●
	Work and employment	2 nd	2 nd	1 st
	Housing	●	●	●
	Tourism and leisure	●	●	●
Self-determination and personal development	Autonomy and resilience	4 th	3 rd	●
	Accessibility in terms of programmes and communication	●	●	●
	Psychological and social competences development	●	3 rd	●
	Life long education and training	1 st	1 st	1 st
	Creativity and emotional expression	●	●	●
	Acceptance and respect	4 th	6 th	3 rd
	Rights and social inclusion	Legal protection	●	●
Performance of roles and functions in public life	●	●	5 th	
Solidarity	●	●	●	
Integration in social networks	●	●	6 th	
Family	4 th	6 th	6 th	
Activation of rights	3 rd	5 th	4 th	

Domains that should have more importance
 Domains that should have an intermediate level of importance
 Domains that should have less importance

The results obtained seem symptomatic as far as, for all types of interventions, persistently betting on centring the actions for enhancing the quality of life, on life long education and training, and on work and employment. It should also be noticed that the priorities defined for actions of creation of opportunities and development of competencies are similar, whereas those that report to transformation of standards and values have a different profile, while also considering as transversally priority areas, performance of roles and functions in public life, integration in social networks and family.

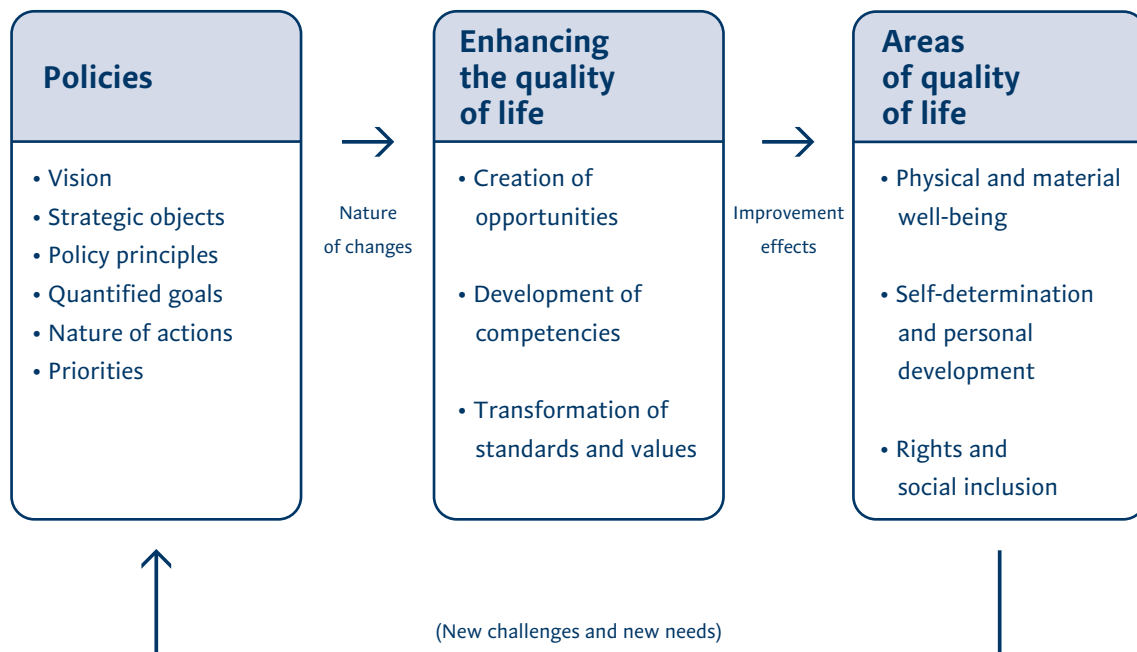
Thus, an exercise such as this enables one to guide the priority axels of action towards enhancing the quality of life. However, a political strategy can not just define a conceptual model, define and rank priorities centred on people. Its governance model is equally relevant (cf. Chapter 9), thus aiming at two types of goals, in a balanced way:

- those related to personal and social results: quality of life and equality of condition for citizens with disabilities;
- those related to design, management and evaluation of policies, programmes, measures and services, understood as quality social services, in design, management and evaluation, for which there has to be maximum management efficiency in condition of equity, while ensuring participation.

PROPOSAL OF A STRATEGY FOR PORTUGAL

The main orientation of this proposal of a rehabilitation strategy for Portugal is enhancing the quality of life of citizens with disabilities, according to the terms presented in Picture 6.

PICTURE 6. **QUALITY OF LIFE AS THE MAIN ORIENTATION FOR A REHABILITATION STRATEGY FOR PORTUGAL**



The underlying idea is that the process for enhancing quality of life is an ongoing and cyclic process, in which fulfilment of a set of goals induces new needs, which feedback the strategic options with new challenges, goals, priorities and actions, acting simultaneously upon the three domains for enhancing the quality of life.

The strategy should:

- follow a **vision** which may guide its contents towards a desirable scenario and which may support its fulfilment within the scheduled timing.
- identify the **strategic goals** that may allow the definition of the most appropriate policies in order to reach the intended results.
- contain **policy guidelines** (and a governance framework that may ensure its execution) that are coherent with the vision and strategic goals.
- establish **quantified targets** that may enable monitoring and evaluating, which may allow the responsible persons to evaluate its results and the stakeholders to exercise their right to participate and to exercise critical surveillance upon its execution.
- define the **nature of the actions** through which each of the policy guidelines shall be fulfilled.
- adopt **priorities** which are adjusted (and adjustable) to the objectives and to the pace at which the defined targets are attained.

In the present case, the exercise should converge into actions and priorities that may generate changes in enhancing the quality of life, which translate into

effects of enhancing the quality of life of people with disabilities, and which open new needs and new challenges.

Considering the specific starting point and considering what seems possible to fulfil, in case it is possible to mobilise the appropriate will power and resources, we are proposing an ambitious vision, which purpose is to point out the path to follow until 2025.

By 2025, Portugal shall ensure the *equality of condition* to people with disabilities, valuing them, creating *opportunities* for them, so they may improve their *quality of life*, and ensuring their full participation in a decent, open and inclusive society.

It is said in this vision that “Portugal shall ensure”, meaning that it is only possible through a strong collective commitment, through a strong participation of the State and with the active involvement of social institutions in general, and not just with the service providing solidary network, either public or profit based, plus the persons themselves and their families, even though they are also fundamental pillars in order to ensure the proposed goal, in a regimen of shared responsibility.

What shall Portugal ensure? “Equality of condition”, a concept defined from the definition of John Baker, among others, for whom the equality of condition, philosophically, is the idea that “people should be as equal as possible regarding their central conditions of life. Equality of condition does not have to do with the attempt to make social inequalities fairer, or to offer people more equal opportunities for becoming unequal, but rather the guarantee of all having basically the same prospects of having a good life.” (BAKER, 2003, adapted).

Thus, the strategy aims at ensuring equal prospects of access to the possible standard of life in Portugal, by 2025, for all citizens, with and without disabilities. Such access shall be achieved by focusing, in a strategic and integrated way, on enhancing quality of life, understood as defined above, and implies the guarantee, by the State, that citizens with disabilities shall be able to participate in a decent, open and inclusive society. Why a decent society? Because, in the way Avishai Margalit (1996) refers, a decent society does not allow any humiliating violence and discrimination, either from institutions upon citizens, or from some citizens upon other citizens.

With which strategic goals can Portugal reach such vision? Considering that one should search for results, both for people, as well as in terms of improved efficiency in the use of resources that can be allocated to the strategy, we propose four strategic goals.

PICTURE 7. STRATEGIC GOALS



The first objective is a direct consequence of the historical heritage of rehabilitation policies in Portugal, and aims at ***ensuring access to rights***, which implies ensuring the mechanisms for its complete fulfilment in terms of civil, political, social, economic and cultural rights, and the acknowledgement that disability is a complex, holistic and integrated reality.

A policy of access to rights has to be integrated, since sectorialisation often generates disconnection between agents and obstructs materialising access, even when formally consecrated and generally desired.

The second goal embodies a new ambition for rehabilitation policies, that ***equality of condition are envisioned as the ultimate goal of such policies***. This new platform implies to keep fighting inequalities between citizens with and without disabilities, and in order for such endeavour to be successful, it depends very much on the capacity to generate effective measures, to appropriately plan the resources destined for it, but also on the transformation of social relations around disability, without which, all endeavours on the side of “production”, in other words, active policies for promoting equality, shall face the obstacles that the present social dynamics create.

Equality of condition means equal opportunities and equal participation in an active and effective way in all domains and equality in terms of results, not determined by each specific situation, which shall be compensated through positive actions.

The third objective should be reinforcing mainstreaming, which implies ***integrating disability issues in policies, programmes and general interventions, complemented by specific programmes, actions and resources, within the framework of and integrated and multi-sectorial political strategy.***

The path of mainstreaming already started to be walked, even if with some resistance and some fears, in some domains and by some players. It is not a path free from risks, ahead of which is the risk of wrong integration replacing specific policies which were yielding results, with losses for citizen. But it is a necessary course, either in order to avoid creation of ghettos which make full participation in public life even more difficult, or so that there is an effective co-accountability by those who manage specific policies. This is also the path to follow for transversality – all policies have to be inclusive of citizens with disabilities. This type of orientation does not imply that specific services disappear, it means that there is a re-orientation, precisely focusing these specific services in the answers to the specific issues to which they can ensure the best responses (or, in some cases, that can only be assured by them), in a complementary way to the responses ensured by the general policies and resources.

The fourth goal is centred on the proper use of resources and in the principle of participation. The intention is that the strategy be fully responsible and transparent, and so all efforts should be undertaken in order to ***grant greater efficiency to resource usage and greater accountability to policies and measures, within the framework of a strict management culture, with the participation of all citizens and social players involved, ensuring high levels of quality of service, and production of responses adjusted to the needs and expectations of citizens.***

For each strategic goal a set of policy guidelines was defined (Table 44). These guidelines do not follow any sectorial logics, but rather a transversal one, precisely due to the nature of rupture that the new strategy intends to bring about, in relation to the tradition of segmenting and sectorialising policies.

TABLE 44. STRATEGIC GOALS AND POLICY GUIDELINES FOR THE NATIONAL REHABILITATION STRATEGY UNTIL 2025

<p>Strategic goals</p>	<p><i>To ensure access to rights</i></p>	<p><i>To aim at equality of condition</i></p>	<p><i>To integrate disability issues into general policies complemented by specific actions</i></p>	<p><i>To grant policies and measures with greater efficiency and accountability</i></p>
<p>Policy guidelines</p>	<p><i>To compensate impacts caused by disabilities</i></p> <p><i>To create opportunities for personal development, while fulfilling the various needs of people and while promoting their social participation</i></p> <p><i>To promote the State's and Social institution's responsibility in the creation of opportunities, and of citizens and their families in searching for them and in properly using those opportunities, as well as in optimising resources and potentials</i></p>	<p><i>To ensure equal opportunities and results, through positive actions</i></p> <p><i>To promote social inclusion through active participation, understood as the capacity to be present, to affect and be affected by all social dynamics</i></p> <p><i>To address, in an interactive way, all political, economic, social, educational and cultural inequalities in a decent, open and inclusive society with acknowledges, values and celebrates diversity as a positive value</i></p>	<p><i>To integrate disability issues in policies, programmes and general interventions, complemented by specific programmes, actions and resources</i></p> <p><i>To integrate and coordinate measures and actions in a common political reference framework, while enhancing sectorial responsibilities</i></p> <p><i>To conceive all disability-related services as an area of general social services</i></p>	<p><i>To create new condition of accountability for policies, programmes and interventions by defining goals and targets which can be appropriately checked and monitored</i></p> <p><i>To adopt transparent and participatory design, management and evaluation systems in which, the different stakeholders are co-accountable and where their active participation is encouraged</i></p> <p><i>To reconcile equity and efficiency in management, promoting quality of services and responses offered to citizens</i></p>

The goals and policy guidelines to be achieved should be consolidated in a global strategy, gathering all the necessary actions, in all specific domains of intervention and, consequently, developed in sectorial action plans that translate, for each area of intervention, the goals of the global strategy. Thus, in order to follow the proposed model, the vision, strategic goals and policy guidelines should be consolidated, and only then **design the general and sectorial action plans, determined and referenced in time, so that mid-term progress evaluations may be carried out.**

Following the suggested general orientation and vision, the policy goals should reflect the holistic approach, in other words, should cover the different action domains for full inclusion and for fulfilling the equality of condition. Accordingly, the proposal presents, for each strategic goal, a set of policy guidelines for enhancing the quality of life and for progressing towards equality of condition, not organised by sectors of political intervention, but according to the goals to be achieved, to the level people are at, and to the level of policies and services.

Within the scope of strategic goal **to ensure access to rights**, the proposals for policy guidelines are centred on:

- **Compensating** disability impacts: in this guideline, the expression “compensating” should not be understood in the traditional sense of “compensation policies”, but rather referring to the intervention which aims at optimising people’s potential and reducing or eliminating intrinsic effects of disability in their life, side by side with the compensatory measures of passive nature, complementary and adjuvant to the activation measures, which should be central and primordial, whenever possible.
- **Creating opportunities** for personal development, fulfilling the different needs of people and promoting their social participation: in order to fulfil this guideline one should try to improve the condition for individual emancipation and for participation in social life; in other words, one should try to increase one’s endowment of cultural and social capital, of knowledge, competencies and social relations.
- **Promoting the State’s and Social institution’s responsibility** in the creation of opportunities, and **of citizens and their families** in searching for them and in properly using those opportunities, as well as in optimising resources and potentials: this guideline is aimed at citizenship rights and obligations, implying that inter-crossing rights and duties among everyone is encouraged – the State, social institutions, citizens and their families – with the understanding that it is up to the State to ensure social rights and to promote active inclusion policies, that social institutions are responsible for solidary actions, either contracted with the State or through the market, for delivering social services to citizens with disabilities and for creating appropriate opportunities so they may use and develop their potentials, and citizens and their families have the right to enjoy the opportunities thus generated and the obligation to search for them and to properly use them.

The expected joint effect from fulfilling these three policy guidelines shall be a very strong step towards ensuring access to rights, for the investment made in people and for the progress in fulfilling policies, of a voluntary and solidary platform, towards a new platform which contracts mutual obligations and ensures rights, at the same time that it creates obligations for all agents involved in rehabilitation policy.

The strategic goal ***to aim at equality of condition as the ultimate policy goal*** adds a new level of demand to policies and measures, since it is not just circumscribed to interventions among people with disabilities, but also includes the relational level by eliminating differences between results in terms of social indicators between these citizens and the others, which implies, on one hand, positive actions for fighting inequalities, and on the other hand, interventions – stimulating ones and/or punishing ones for non compliance – centred in ensuring that society does not deny opportunities to these citizens or creates them only in a discriminatory way. Three policy guidelines shall fulfil this goal:

- ***To ensure equal opportunities and results***, through positive actions: the intention is that the system of players of rehabilitation policies takes responsibility for ensuring social equity in all actions and measures, particularly emphasizing the importance of guaranteeing that all conditions are created so that the opportunities made available are materially fulfilled and become transformed into equality of results, eliminating the risk of formal creation of opportunities with no real conditions of success, which, in case it actually occurs, ends up leading to waste of resources and discouragement of citizens.
- ***To promote social inclusion through active participation***, understood as the capacity to be present, to affect and be affected by all social dynamics: the understanding of this guideline is that production and/or improvements in competencies should be transferred as better chances of life for citizens with disabilities, in other words, it requires that the players of the rehabilitation system act in a way as to promote participation of citizens with disabilities in the collectivities life at all levels, fighting against the tendency of being closed in specific issues of their condition.
- ***To address, in an interactive way, all political, economic, social, educational and cultural inequalities*** in a decent, open and inclusive society which acknowledges, values and celebrates diversity as a positive value. The two former policy guidelines can only be fulfilled through a general change of policies related to inequalities. Even though this strategy is focused on people with disabilities, it is known that the equality of condition can only be achieved if significant advancements are made in the fight against different types of inequalities in the Portuguese society. The intention of this guideline is to stress the idea that measures ensuring the equality of condition for citizens with disabilities have to be generated in an environment where the same type of attitude also

exists in relation to other factors of inequality, through the combined interaction of different policies.

The two first strategic goals should lead to the adoption of policy guidelines centred on goals of personal and social results, such as enhancing the quality of life and ensuring the equality of condition for citizens with disabilities. The third and fourth strategic goals have a different focus. They should lead to the adoption of policy guidelines centred on objectives of design, management and assessment of policies, measures and actions, with the understanding that the services provided to citizens with disabilities are social services, that should be provided with quality, and respecting the principle that design, management and evaluation of policies, measures and actions should be conceived in order to achieve maximum management efficiency, in condition of equity, while ensuring citizens' participation.

Thus, the strategic goal to integrate disability issues into general policies complemented by specific actions, within the framework of an integrated and multi-sectorial political strategy leads to policy guidelines centred on political choices, planning of measures and design of services to be provided:

- **To integrate disability issues in general policies, complemented by specific actions:** the central point of this guideline is that it reverses the order in which social responses should be searched. Although in the past the intention was to give priority to the development of specific support systems, and complementarily integration in the general systems, now the intention is to gather all required endeavours and means so that people are integrated into the general systems, whenever possible and appropriate, with the specific measures and support fulfilling a complementary role to the former one, either because of being oriented to specialised services, or because of being supplementary and with additional effects in relation to the resources allocated to general policies to which citizens with disabilities should have access according to equality of condition.
- **To integrate and coordinate measures and actions** in a common political reference framework, **while enhancing sectorial responsibilities:** it implies a great effort, namely by the State, in integrating and coordinating policies and interventions, as well as it implies the existence of a mechanism for trans-sectorial coordination that ensures that policies are executed and their performance monitored (please refer to Chapter 9).
- **To conceive all disability-related services as an area of general social services:** this guideline implies that the approach that services are aimed at persons and at their set of needs, is generally advanced within the logics of service to the citizen, and not segregated or divided into compartments, according to the logics of administrative organisation, in other words, it aims at re-organising service provision, in order to ensure the continuum of services centred

on people, coordinated and based on the community, mobilising partnerships among territory players, supporting the organisation and development of life projects in a logic of case management.

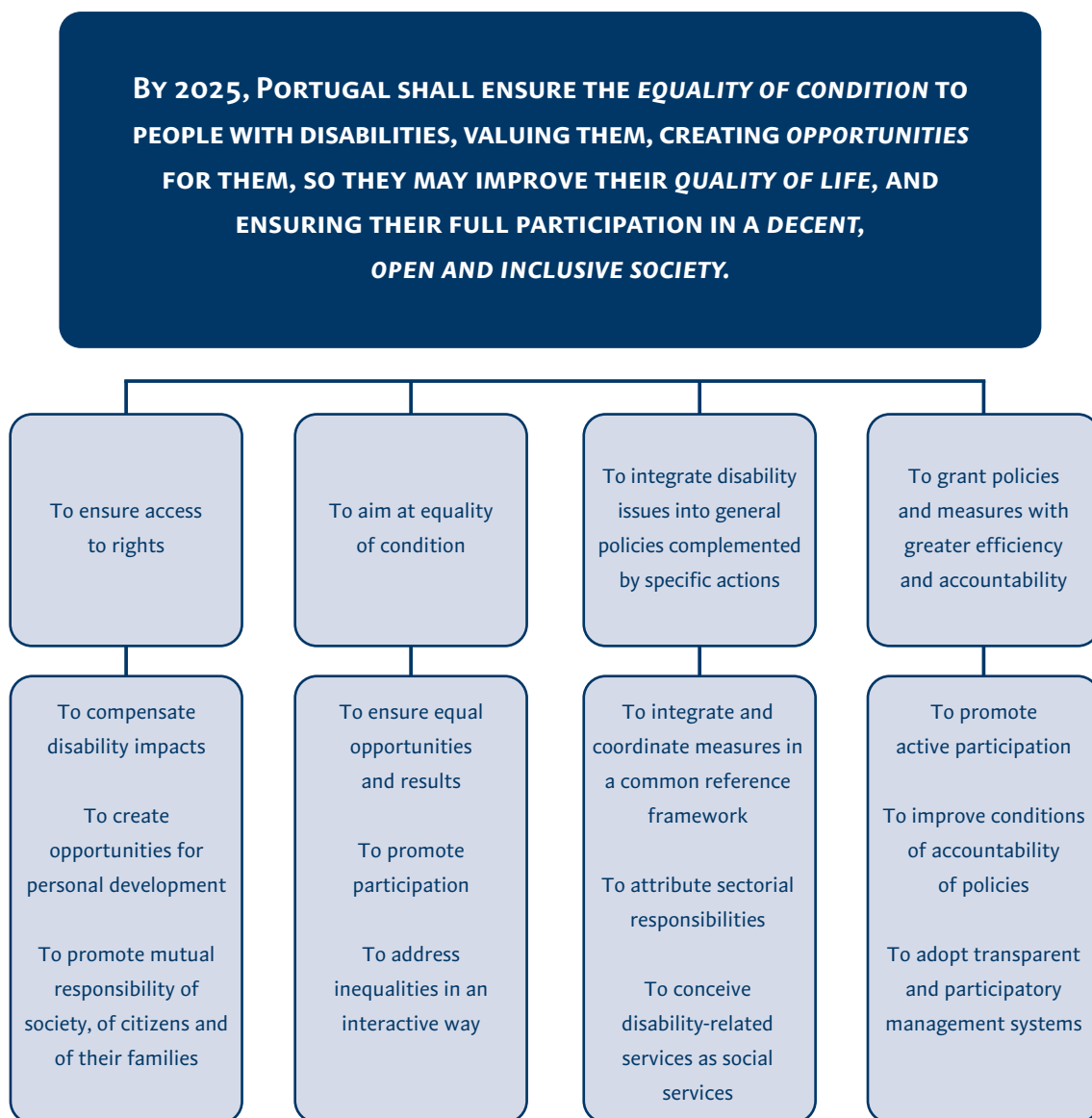
The fourth strategic goal – ***to grant policies and measures with greater efficiency and accountability, within the framework of a strict management culture, with the participation of all citizens and social players involved, ensuring high levels of quality of service, and production of responses adjusted to the needs and expectations of the citizens*** – is quite demanding in terms of planning, design, management and evaluation of policies, measures and services. The policy guidelines that embody this strategic goal are centred on reconciling equitable access to services and participation at all stages of the policy management cycle, with the purpose of achieving efficient resource usage.

- ***To create new conditions of accountability for policies, programmes and interventions by defining goals and targets that can be appropriately checked and monitored:*** this policy guideline aims at increasing the level of control over performance of the rehabilitation system. To define targets and to check whether or not they are achieved increases the agents' accountability and increases guarantees of transparency for those measures. As a matter of principle, all measures to be included in action plans, either general or sectorial, should comply with this guideline.
- ***To adopt transparent and participatory design, management and evaluation systems, in which the different stakeholders are co-accountable and where their active participation is encouraged:*** this guideline intends to improve the level of fulfilment of the principle of participation at all stages of the management cycle of policies, measures and services, from design to monitoring and evaluation of results.
- ***To reconcile equity and efficiency in management, promoting quality of services and responses offered to citizens:*** this guideline intends to introduce, in a generalised way, guarantees of efficiency in the use of available resources, making such efficiency compatible with increased quality requirements and with equitable access to services. This can be achieved in different ways, as is being done in other EU countries (Chapter 7), but it always implies a greater connection between allocation of resources and performance by service providers, while placing the citizen-client at the centre of the system.

The set of policy guidelines thus defined completes the reference framework of the strategy proposal for Portugal. Picture 8 summarises the components of such strategy: vision, strategic goals and policy guidelines.

PICTURE 8.

SUMMARY OF THE PROPOSAL FOR A STRATEGY FOR PORTUGAL UNTIL 2025, FOR SOCIAL INCLUSION PEOPLE WITH DISABILITIES



Based on the accumulated experience and reflections, and on the information gathered along the work, a new horizon opens up for rehabilitation policies in Portugal with the present proposal, as well as a contribution for the definition of such a new horizon, with the construction of a strategy model that can be taken up again, discussed, corrected and deepened by the system of players of rehabilitation policy.

Even though it is not part of the dynamics of this Study to move towards designing the action plans themselves, however, in order to fulfil the strategy, the nature of the measures and actions that could embody each of the policy guidelines are defined and presented. Some examples of measures that could correspond to actions of that nature were chosen because they refer to essential or sensitive areas of intervention are also proposed. This is the contents of the following item.

ACTION DOMAINS

One of the challenges for a successful strategy has to do with transposing it into practice. Supporting such operationalisation, we now present the nature of actions that should be conceived and executed in order to leverage the results for each policy guideline, and examples are given of two measures per type of action for enhancing the quality of life, how they could cover the diversity of domains of quality of life.

This exercise was developed with the understanding of the risk involved in such examples, in case they are mistaken with the outline of an action plan. Only two measures are presented for each type of action for enhancing the quality of life, considered as relevant and paradigmatic, and no further developments are systematised, regarding the set of measures to undertake, as this role should be performed by the action plans to be developed within the scope of the strategy.

The examples chosen are based on the critical analysis of the former and present experience, carried out by the team and by the group of people and entities that followed the Study.

The contributions that were gathered converge towards the idea that there is a set of domains of intervention which are urgent, which is then reflected in the choice of the examples, even though these include others as well. The priority domains are the following:

- **Life long education and training**, as citizens with disabilities in Portugal have very low levels of academic qualifications and access professional qualifications which are also very low, and this obstacle becomes a real hindrance and a factor which legitimates their exclusion or their integration in the labour market in occupations of poor qualifications, with precarious professional situations that yield low incomes.
- **Work and employment**, since the differential regarding the levels of employment of citizens with disabilities, specially for some types of disability, is huge, reflecting the difficulties of access to a job, of developing professional carriers and of keeping a job, particularly in the case of acquired disabilities.
- **Income and social allowances**, as from the data collected it appears that disabilities are associated to great vulnerability at the level of income and are a factor of impoverishment, with consequences that then get reflected in many aspects of access and effective use of rights and in the precariousness of the present social status of many of these citizens.
- **Activation of rights**, as it results, from the research made, that there is a situation of generalised resignation by citizens with disabilities regarding their present social status, which weakens progress in real access to rights, and requires a strong intervention in terms of promoting a new social attitude in face of disability issues, of empowerment of citizens and of support to

activation and mobilisation of their rights, granting greater social visibility and non-conformism to these citizens and to their problems, which is indispensable for achieving structural changes in their legitimate aspirations and for their personal and social enhancement, and in their living conditions and perception, as well as in the perception of the remaining citizens.

When choosing the examples and architecture for the whole strategy, we are bearing in mind that one of the results to which our research led was that Portugal has a rehabilitation system which is fragmented by specialities and very much oriented towards congenital disabilities – specially at the level of social responses – whereas the universe of the citizens with disabilities includes a much wider group of citizens that have acquired disabilities along their lives. This latter group seems to have less access to effective rehabilitation services, while both groups are presently facing inadequacy of a fragmented model of intervention, in face of the integrated nature of people’s needs. Both factors condition the effectiveness of the rehabilitation system, on one hand because they leave “blank areas”, not covered by necessary services, and on the other hand, because there are efficiency and quality losses in services provided to citizens due to the lesser rationality of the service provision network, comparing to what it legitimately wants to achieve.

We try to conceptually clarify the contents of each policy guideline for each of the strategic goals which were expounded, and try to define the model from which action plans can be built by using a summary table for each guideline, where definitions of the nature of actions to undertake and Examples of measures within the scope of enhancement of quality of life are included, which could be included in the action plans for implementing the strategy. Regarding each of these examples, the domain of quality of life for which improvement it would contribute is also identified.

Strategic goal

“To ensure access to rights, and to ensure the mechanisms for their total fulfilment, while acknowledging that disabilities are complex, holistic and integrated reality.”

Within the scope of this strategic goal, and of the policy guideline ***compensating disability impacts***, all initiatives aiming at eliminating added difficulties due to the effect of changes in the persons’ structures and functions should be considered (Table 45).

TABLE 45. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE COMPENSATING DISABILITIES IMPACT

Policy guideline		<i>Compensating disability impacts.</i>
Nature of actions to be undertaken		Initiatives aiming at eliminating added difficulties due to the effect of changes in the persons' structures and functions.
Examples measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To re-evaluate and re-formulate social allowances, trying to maximise their effectiveness as: (a) instruments for compensating people's added costs due to disability; (b) mechanisms for ensuring the necessary income for a life with dignity; (c) incentives for an autonomous life, namely for participation in active and professional life. (Domain of income and social allowances).</p> <p>To invest in supporting employment, firstly within competitive contexts, by mobilising, supporting and rendering the employing entities accountable, complemented by support measures to active life not accommodated within a work relationship, promoting opportunities for realising the active potential of citizens whenever it is not competitive in face of the demands of the labour market. (Domain of work and employment)</p>
	Development of competencies	<p>To ensure the operation of a network for initial qualifications and vocational rehabilitation, accessible to all citizens that might need it, integrating transversal responses from the education and vocational training system, as well as specialised complementary responses. (Domain of life long education and training)</p> <p>To promote early intervention in cases of acquired disabilities, in order to minimise loss of contact with the labour market, combining rehabilitation, professional reconversion and re-adaption, and supported employment. (Domains of life long education and training, and work and employment)</p>
	Transformation of standards and values	<p>To create a certification of social quality for companies that uphold, as their requirement, integration of citizens with disabilities and adaptation of workstations and work contexts to their specific needs. (Domain of work and employment)</p> <p>To define investment goals in Research and Development (R&D) in assistive products for people with disabilities, for instance, through the existence of research centres in rehabilitation engineering, and centres of competency for supporting mobilisation of technology and of technological devices. (Domain of autonomy and resilience, and all those where applications are developed)</p>

The examples given are related to some central aspects that need to be rethought in inclusion policies. The measures which in the past addressed disabilities according to an indemnifying approach (traditional sense of the compensatory concept) ended up tending to correspond to minimal social support and to promote the abandonment of, or non-entrance in, the labour market of many citizens with disabilities with the potential to integrate it. Social allowances should be conceived, whenever possible, as springboards for social inclusion and not the opposite, and so, reorientation of the social allowances policy for disability towards improving the relationship of social allowances with income from work seems to be a relevant element, in order to encourage entrance into the labour market. Thus, it is important to favour the promotion of active and professional life, investing financial resources and adopting support strategies of eminently positive nature, in detriment of opting for mechanisms for guaranteeing income, as much as possible and/or through reconciling income from work and income from social allowances, within socially acceptable limits. To foment integration in job solutions is also a fundamental element for actual social inclusion of people with disabilities which active potential is not competitive in face of the demands of the labour market.

Even though in a different field, not so much centred on the relationship with work, but rather with freedom of movements and participation in public space, also the system to grant assistive products needs to be improved. Assistive products are an element of great importance, in certain types of disabilities, for social emancipation and for exercising freedom, as well as for treating citizens with dignity. The system should not be fragmented and with different rules among different Administrative departments, it should rather be an integrated system with common rules. As this is a domain where availability of resources is scarce, in face of the dimension of needs, the financial system for granting assistive products needs to be restructured, clearly defining its philosophy and principles, its goals, the players, their respective roles and responsibilities, the methodology of intervention, and the mechanisms of coordination and control. Improved efficiency should be connected to the perception that in situations such as this one, positive differentiation is an instrument of social equity.

This same social equity demands that people with disabilities be given real opportunities to develop autonomy and to improve their social condition, for which, it is fundamental that the rehabilitation system comes close, as quickly as possible, to the guarantee that the qualification network and the vocational rehabilitation network are really accessible to all citizens in need of such specific interventions. In the same way, early intervention in the cases of acquired disabilities has demonstrated that it is an important factor for preserving social ties and in particular for the participation of these citizens in the labour market.

Within the scope of policy guideline ***to create opportunities for personal development***, satisfying the different needs of people and promoting their social participation, following are included the actions aimed at decreasing activity limitations and distributing in a more equally social opportunities and opportunities for personal enrichment, so that they may reach in a more and more intense way people with such limitations (Table 46).

TABLE 46. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE CREATING OPPORTUNITIES FOR PERSONAL DEVELOPMENT, SATISFYING THE DIFFERENT NEEDS OF PEOPLE AND PROMOTING THEIR SOCIAL PARTICIPATION

Policy guideline		<i>Creating opportunities for personal development, satisfying the different needs of people and promoting their social participation</i>
Nature of actions to be undertaken		Actions aimed at decreasing activity limitations and distributing in a more equally social opportunities and opportunities for personal enrichment, so that they may reach in a more and more intense way people with such limitations.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To guarantee universal access to a needs and potentials assessment, at the time the disability is signalled, either if it is congenital or acquired, made by the centres of competency, in order to determine which are the needs, the problems to solve, the potentials to explore and to develop the individual plans of habilitation/rehabilitation, by using the ICF as an analytical reference for assessment. (Domain of activation of rights)</p> <p>To guarantee the existence of local support centres responsible for supplying information, advice and advocacy, and that can be a contact point for the citizen with the rehabilitation system, and that may facilitate access to services, through the case management model, guiding the execution of individual plans, combining material resources and service provision, and that can evolve into preparation of personal budgets. (Domain of activation of rights)</p>
	Development of competencies	<p>To promote access of citizens with disabilities to higher levels of education and professional qualification, namely by education and training courses until 12th grade, and schooling until 18 years of age, according to the development of their potentials. (Domain of life long education and training)</p> <p>To fight illiteracy and to create the conditions for accessing opportunities of life long education and training, within the scope of general education and vocational training policies, namely within the Initiative of <i>New Opportunities</i>. (Domain of life long education and raining)</p>
	Transformation of standards and values	<p>To raise awareness among citizens, their families and significant stakeholders for the importance of integration in general resource networks, for their own mobilisation and enhancement. (Domain of activation of rights)</p> <p>To ensure the existence of information on daily activities and public life in supports adapted to the different types of disability. (Domain of accessibility in terms of communication and programmes)</p>

The choice for these measures as examples of what should be put on the action plans is based on the need to transform the starting point in terms of acquisition of competencies. This domain is of the utmost importance, as differentiated access to resources that enable personal enrichment, becomes a factor for legitimating differences of results in terms of opportunities along one's life, both in the eyes of the persons with disabilities themselves and in those surrounding them.

Guaranteeing universal access to needs and potentials assessment, made by the competency centres at the time the disability is signalled, either if it is congenital or acquired, in order to determine which are the needs, the problems to solve, the potentials to explore, is the starting point from where the joint work of technical staff and citizens can be designed, and which can result in greater levels of autonomy and social participation. Periodical review of such assessment is a factor that guarantees that any acquired potentials were not lost, and that eventual new problems were not neglected, and that the social ties of the citizen were kept, through the creation of structures to follow up the development of the situation, which can contract and define the required and appropriate actions for each case.

This corresponds to a whole new approach, with a shift from the disability paradigm, to the competence paradigm, in other words, with the concern of valuing potentials, capacities, as leverage for the rehabilitation courses and for enhancing higher levels of quality of life.

Assessment of one's disabilities, while still being necessary, shall be relevant for determining impacts and the costs of disabilities, and for repairing damages and losses resulting from acquired disabilities, and should only occur after rehabilitation processes, after optimising and stabilising the different functional frameworks.

Considering the traditional assessment of disabilities, this model has the great advantage of being based on a holistic approach of the human being, and not just upon one's capacity for work, and of creating an integrated plan for assessing the needs of people with disabilities, either congenital or acquired, of all types, valid for all axes of inclusion policies, and not restricted to policies of employment and social protection. On the other hand, it enables to follow-up on the development of each person's situation.

So that such follow-up may work, it is very important to develop mobilisation factors for local communities, particularly for those where spontaneous dynamics that leveraged the development of the present network of services were more fragile or non-existent. So the State should, either on its own or through contracts, ensure proximity support services, to provide information, counselling and advocacy, which can be solid contact points between the citizens and the rehabilitation system. Such development shall generate effects not just at

the level of covering needs, but, above all, shall also ensure increased awareness of the citizens' rights and obligations, and shall facilitate their individual emancipation and participation in social networks.

These support centres shall become facilitators of citizen's access to services, with the advantage of considering the citizen as a whole, and so, through the case management model, may be guided towards preparation of individual action plans, combining material resources and service provision. Thus, the level of information available to the citizen on the existing resources shall increase, as well as citizen's freedom of choice and definition of priorities, so important for his/her definition of his/her life project. The example, already tested in other countries, of preparing personal budgets is one of the possibilities to be developed, as it maximises freedom of choice as well as the citizen's power over service providers, and so it is one of the possible ways for increasing service efficiency without losing equity.

At the micro level, these transformations shall introduce changes with strong effects, mainly structural ones, whereas macro policies should focus on more demanding goals in their relationship with citizens with disabilities. It has been known since very long that equal access, often just formal, is insufficient for real inclusion of persons and groups with specific needs. Now, when it has to do with access to knowledge, such as in education and training, inequalities generated by this way gain a tremendous weight in the definition of possible courses of life.

Quite often there is a great deal of resignation regarding the association between disabilities and low levels of performance at school or acquisition of just basic professional qualifications. The spiral of social exclusion that opens up in this way must be cut off once and for all. Thus, the importance of promoting access of citizens with disabilities to higher levels of education and professional qualification, through actions of positive support in order to achieve those goals.

In this area, it is fundamental that these citizens follow the gradual increase of educational levels and basic qualifications as they are defined into higher and higher levels. To not achieve them makes exclusion more serious, as it increases the gap in face of the general standards of society. For instance, the goal of ensuring education until the age of 18, and education and training courses until 12th grade for everyone is a goal that should be defined as the most basic level also for citizens with disabilities, eventually by launching a new strand for the Initiative *New Opportunities*.

The information collected clarifies that among the adult population, disabilities are associated to low literacy and low levels of education, which contribute to different types of conditioning, in accessing opportunities, in exercising rights, in social participation, in one's perception of one's own condition. Therefore, so that there are no lost generations, the strategy should also be guided towards recuperating the potentials of the adult population, fighting illiteracy

and creating conditions for accessing life long education and training, within the scope of general policies for education and vocational training. Thus, these policies would be more inclusive and the levels of discrimination in accessing formally available resources would decrease, with direct benefits for all citizens and with gains in terms of social cohesion.

Within the scope of policy guideline to promote the State's and Social institution's responsibility in the creation of opportunities, and of citizens and their families in searching for them, and in properly using such opportunities, as well as in optimising resources and potentials are included the stimuli so that at all levels of life in society, full integration of citizens with disabilities is actively searched for, while these, in turn, should take up the duty of acting in such a way that such opportunities are fully taken advantage of (Table 47).

In this domain, the tradition has been of essentially holding the State responsible and of benefiting from the good-will and commitment of institutions of solidarity. However, in order to make significant advancements the approach must be changed. Inclusion supposes activation of policies and commitment by the State; it includes maximising social solidarity, but it can only be fully achieved if all social players accept that the goals of social inclusion concern them as well, whatever their fields of action.

The fact that some key players in contemporaneous societies do not take responsibility for the issue of disabilities, specifically for acquired disabilities, generates obstacles for inclusion and social participation, which are difficult, or even impossible to overcome without a new culture of responsibility.

The idea of this policy guideline is to promote such a culture of responsibility that may turn social inclusion into a natural component of citizenship duties, along with other ones, instead of circumscribing it to more sensitive or mobilised sectors, for whatever type of reason.

In this field, the information which was gathered made it clear that the levels of participation in the labour market are strongly unfavourable, which makes of this one of the main fields where such culture of responsibility needs to be promoted by all means. At present there is support from the State that practically is not used by companies, active employment policies with strong potential for inclusion but with very limited application, little persistence in supporting return to or retention in the labour market by those who were affected by an accident or some chronic disease at some point in their life.

TABLE 47. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE PROMOTING THE STATE'S AND SOCIAL INSTITUTION'S RESPONSIBILITY IN THE CREATION OF OPPORTUNITIES, AND OF CITIZENS AND THEIR FAMILIES IN SEARCHING FOR THEM, AND IN PROPERLY USING SUCH OPPORTUNITIES, AS WELL AS IN OPTIMISING RESOURCES AND POTENTIALS

Policy guideline		<i>Promoting the State's and Social institution's responsibility in the creation of opportunities, and of citizens and their families in searching for them, and in properly using such opportunities, as well as in optimising resources and potentials</i>
Nature of actions to be undertaken		Stimuli so that at all levels of life in society, full integration of citizens with disabilities is actively searched for, while these, in turn, should take up the duty of acting in such a way that such opportunities are fully taken advantage of.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To adopt positive actions for increasing openness by employers and to actually have effective stimuli in active employment policies. (Domain of work and employment)</p> <p>To legally foresee the possibility of resorting to a personal assistant and to promote the use of personal assistants. (Domain of psychological development and social capacities)</p>
	Development of competencies	<p>To adopt measures of empowerment of citizens with disabilities, of their relatives and significant stakeholders, centred in encouraging the adoption of an autonomous life and one of social inclusion, whenever appropriate, through participation in professional life. (Domain of autonomy and resilience)</p> <p>To define the professional profile, promote their training and support the activity of professionals endowed with competencies for advising companies and institutions, which may act as mediators between the organisations and the citizens, and as facilitators for their integration in appropriate work contexts and positions. (Domain of work and employment)</p>
	Transformation of standards and values	<p>To develop awareness and to commit municipalities – as reference entities – and other local social players in the construction of an open society, distinguishing municipalities without barriers. (Domain of acceptance and respect)</p> <p>To promote crossed duties among all social players for maintaining the relationship of injured persons and victims of cronical diseases with professional life, namely by developing the legal mechanisms that may offer injured workers or workers with cronical diseases the actual right to re-establish their working capacity, to recover for active life, as well as for their professional reintegration and/or replacement, while holding employers more responsible for retaining and reintegrating such workers. (Domain of work and employment)</p>

In order to reverse this situation it is necessary to act in an intense and strong way in the field of transformation of standards and values. Two examples are highlighted, of a change of attitude and of encouraging existing good practices. As far as the construction of an open society, without barriers, the commitment of municipalities and of other local social players, granting visibility to good practices which were undertaken, through dynamics of social recognition, thus enabling and fomenting their dissemination. At the level of return to work of those that experienced an acquired disability, the provisions of the Labour Code need to be implemented in order for companies to develop greater responsibility for these people who were employed at the time they were affected in their future professional course, by maintaining them and being co-responsible for their rehabilitation, participating in their reconversion into other functions, more appropriate for the new situation, or adapting the workstations so that they may remain in the company, whenever possible. It would also be appropriate to extend the strategy of returning to work or keeping the job, for those who acquired a disability as a consequence of other accidents and diseases.

A new attitude of openness is also required in the domains of the citizens themselves and of the social contexts where they live. It is considered that planning the intervention of personal assistants and of job mediators are two measures that can significantly help to overcome obstacles, often small ones, but which become gigantic in the daily lives of people, either for their autonomy and participation, or for their integration in the labour market. Portuguese policies have been very much centred in the acquirement of competencies by citizens with disabilities, but it is necessary to move from there towards policies centred around moving from acquirement of competencies to opening up possibilities, out of which individual autonomy may be stimulated by personal assistants, and the difficulties along the path of integration in a job may be minimised by the intervention of job mediators.

The effect of these measures would be strongly leveraged by the adoption of a set of other measures specifically guided towards empowerment of citizens, of their relatives and of other significant others, encouraging the adoption of an autonomous life and one of social inclusion, namely through the professional way, whenever possible.

Within a new context of accountability and empowerment, many existing measures, namely in the area of employment and in the area of social inclusion, shall find the grounds for achieving better results, and the State shall see the effects of investment in people and in their enhancement being maximised. In turn, citizens shall see their endeavours being better rewarded.

Strategic goal

“Aiming at equality of condition as the ultimate policy goal”

The three policy guidelines for this strategic goal correspond to a structural change in the goals to be achieved by Portuguese society. It is understood that the strategy should promote access to rights and with even greater ambition, should aim at equality of condition, which implies harmonised efforts in order to eliminate inequalities, either resulting or not from disabilities. Effectiveness of the measures included in the strategic goal of access to rights shall create new conditions for promoting equality, and so its fulfilment is a necessary condition in order to achieve this goal.

Actions should be developed here in order to maximise the effect of the former ones and in order to make social players more demanding, not just regarding the need for participation and inclusion but, besides that, also regarding equal rights. In other words, here would be included measures aimed at progressive elimination of participation restrictions, ensuring access to equal opportunities of enhancement and personal fulfilment, and equal participation in the benefits obtained from proper use of the opportunities made available (Table 48).

Very often, participation restrictions derive from fragmented measures and services, that become incoherent or disarticulated and that leverage, in a negative way, access to opportunities. So, examples of measures to be taken are given with two measures of creation of necessary opportunities so that the interventions themselves actually become accessible and endowed with the required quality.

TABLE 48. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE ENSURING EQUAL OPPORTUNITIES AND RESULTS, THROUGH POSITIVE ACTIONS

Policy guideline		<i>Ensuring equal opportunities and results, through positive actions</i>
Nature of actions to be undertaken		Measures aimed at progressive elimination of participation restrictions, ensuring access to equal opportunities of enhancement and personal fulfilment, and equal participation in the benefits obtained from proper use of the opportunities made available.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To make services and resources available for supporting equality of condition, complementary to general resources, according to a logic of positive actions, available and accessible to all, independently of their geographical location, of their social context or economic status, with special focus on transitions between different stages of one's life cycle. (Domain of integration in social networks)</p> <p>To guarantee universal access to goods, services, transportation, etc. (e.g., to ensure accessibility – physical and economical – to the multimodal public transportation system; to promote accessibility in residences for people with disabilities). (Domain of mobility)</p>
	Development of competencies	<p>To adopt measures that may enable universal access to information, both for public services, and for private ones. (Domain of accessibility in terms of communications and programs)</p> <p>To adopt a plan for empowering and qualifying relatives of people with disabilities centred on the development of competencies for effective social participation. (Domain of integration in social networks)</p>
	Transformation of standards and values	<p>To carry out recurring public campaigns for raising disability awareness, focusing on rights and on people with disabilities, and thus promoting their image as and integral party of the community with full rights. (Domain of acceptance and respect)</p> <p>To adopt measures of positive discrimination for citizens which social condition combines a situation of disability with vulnerability to poverty, at the time of planning programmes and measures. (Domain of solidarity)</p>

Support services and resources, with special consideration for those falling upon times of transition between different stages of the person's life cycle, generally associated to transition in services provided (e.g., to create individual plans of transition from school to work; to adopt an integrated rehabilitation and reintegration plan for victims of disease and accidents; to support transition between services, whenever necessary, such as, between the hospital and the community or between specialised services and regular services), have greater importance in this context.

Within this scope, the introduction of services for disabilities management is quite urgent, in order to prevent and to avoid early abandonment of jobs and to ensure that active citizens with acquired disabilities, as a consequence of diseases and accidents, namely professional ones, return to work, thus opposing dynamics of social de-insertion, while preserving work and social ties, as well as the citizens' dignity, through making work capacity profitable and by making professional and social contexts appropriate.

Within the extremely demanding environment of globalised modern societies, non-access to information in equality of condition is a factor for social exclusion, as it limits knowledge of social opportunities, as it restrains social participation, as it circumscribes the excluded to restricted universes which impoverish their acquirement of social competencies. This is why it is suggested that new measures that may allow people with disabilities to have full access to information, both in public services, as well as in private ones be seriously studied (e.g., to develop basic training in Sign Language in the optics of the user, for key professionals serving people with disabilities; to favour personal service to families of people with disabilities).

Research made highlights the need to encourage demand, in other words, to take up measures that may raise awareness for the risk of exclusion and for integration in society. In order to reverse the tendency for the subordinate condition to become "natural", measures have to be taken in order to endow people with disabilities and respective significant others of the necessary competencies for effective social participation, which can lead to a level of empowerment and qualification of families, aimed at removing such serious obstacles to equality of condition.

On the side of the surrounding society, one has to insist in the type of efforts to promote a new social attitude in face of disabilities, focussing on rights and on people with disabilities (e.g., using images of people with disabilities in regular advertisements, disseminating good practices in the process of participation of these people), thus promoting their image as an integral party of the community, with full rights. No inclusion is possible in a society predisposed towards exclusion, and such cultural and psychological predisposition has to be removed, so that equality may exist.

The final picture obtained from the empirical research carried out within the scope of our Study gave very clear indications on another phenomenon which is critical for achieving equality of condition – the association between disabilities and vulnerability towards poverty. This association results from the incapacity to revert the tendency for impoverishment of people with certain characteristics that become dependent upon networks of family solidarity. Now, families do not have equal access to economic, social and cultural resources, and so for families living in conditions of economic, social and cultural vulnerability, a situation of double vulnerability to exclusion is created. Such fact, plus the intensity of its incidence justify a strong action before families with such double vulnerability, through the development of harmonised and sufficiently strong measures to fight the presently strong tendency for reproducing this double vulnerability with aggravated effects of social exclusion.

These orientations converge towards the need for measures that may contradict inertias, which promote the reproduction of inequalities. Fighting such inertia has to do with strong measures for encouraging citizens with disabilities to participate in all spheres of social life, thus influencing society at all domains, rather than just intervening in those that have to do with defending their own condition. That is the scope of actions to be developed within policy guideline to ***promote social inclusion through active participation, understood as the capacity to be present, to affect and be affected by all social dynamics*** (Table 49).

TABLE 49. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO PROMOTE SOCIAL INCLUSION THROUGH ACTIVE PARTICIPATION, UNDERSTOOD AS THE CAPACITY TO BE PRESENT, TO AFFECT AND BE AFFECTED BY ALL SOCIAL DYNAMICS

Policy guideline		<i>To promote social inclusion through active participation, understood as the capacity to be present, to affect and be affected by all social dynamics</i>
Nature of actions to be undertaken		Encouraging citizens with disabilities to participate in all spheres of social life, thus influencing society at all domains, rather than just intervening in those that have to do with defending their own condition.
Example of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To foment and encourage structured actions for supporting autonomy, at local level, involving participation of citizens with disabilities as well as their families and representative associations. (Domain of autonomy and resilience)</p> <p>To promote the involvement of people with disabilities in cultural activities and activities of social participation. (Domain of integration in social networks)</p>
	Development of competencies	<p>To introduce, in qualification and personal development programmes, curricular components aimed at re/activating personal and social competencies, favouring activation and inclusion. (Domain of psychological development and social capacities)</p> <p>To invest in the development of competencies and in the promotion of actions to facilitate performance of roles of protagonism in civil society and in public life (e.g., to encourage the creation of peer support groups). (Domain of performing roles and functions in public life)</p>
	Transformation of standards and values	<p>To adopt an approach of confidence regarding the potential autonomy that people have, supporting them directly so that they may access services and resources, thus decreasing their institutional dependence. (Domain of autonomy and resilience)</p> <p>To institute mechanisms of purveyor's office for citizens with disabilities, at local level, for relationships with Local Administration and with decentralised services of the State and at national level for relationships with the Central State. (Domain of activation of rights)</p>

The paradigm of quality of life is based on the idea of individual autonomy and citizenship. Reciprocal openness and the dialogic relationship between citizens and social contexts, require social understanding of what difference is, and of how to consider and to treat it. The development of models of intervention in this domain, from patient to citizen, implies that the topic of individual autonomy progressively increases its importance. Now, if promoting such autonomy is part of the whole work developed by the rehabilitation system, it is an activity that can be intentionalised. Considering the existence of personal assistants and of a network of services and support, and considering the efforts of empowerment, there are conditions for giving a strong impulse to the autonomous life of many citizens that presently have strong dependence on the soundness of their social context, namely of the family, where they were born and/or live.

Participation and adoption of protagonism in the life of a community is not something that can be ordered by decree, it is conquered by each individual, but that can and should be encouraged and promoted. The strategy developed herein implies that such goal is valued. That is why examples are given of what an action plan could do in this domain, with incentives that would create new opportunities for individual autonomy, such as the support offered so that more people with disabilities can autonomously manage their own resources, stimulating independent life, creating support dynamics to autonomy, and, at local level, involving the participation of citizens and their families, and representative associations.

This approach also implies the expansion of policies into areas that have received less attention and that aim at the involvement of people with disabilities in cultural activities and of social participation, such as promoting participation in, and coordination of, services by the users themselves, or promoting that people with disabilities vote, by making it more accessible, considering the already existing technological resources. This effort of openness to new opportunities is in harmony with pathways in the development of competencies.

The information collected by the present Study is impressive for the level of resignation it exposes, and so it suggests that it is necessary to promote the development of programmes aimed at re/activating personal and social competencies, improving the self-concept and stimulating reactions to all types of fatalist discourses, as happens with other vulnerable groups to social stigmas.

Within this context, it becomes important that citizens have role-models for developing their potentials. The level of prominence Portugal achieved in the Paralympic Games, for instance, encouraged sports practice and created role-models in this domain. In Portugal we lack citizens with disabilities that, for their performance and responsibilities in public life, may fulfil this stimulus to enrichment in other spheres of action. Policies may and should give visibility to people who do have such potentials and, in that way, specially stimulate the younger

ones undergoing training, so that they may progress and value themselves ⁽¹⁷⁾. The State and civil society should invest in the development of competencies and promotion of actions that may facilitate the performance of roles of protagonism in civil society and in public life (e.g., stimulate the creation of peer support groups) and citizens that stand out may help the community to develop its own levels of acceptance and respect through greater participation in public life.

Increased respect for citizens has to do with the level of confidence in their self governance. Traditionally, these citizens were sheltered in institutions and, even though the situation has changed significantly in the last decades, they are still strongly connected to such institutions. A different type of approach may be taken, which increases freedom of choice and which is a practical exercise of individual autonomy, as happens with individual budgets, in which, after the needs have been diagnosed, an individual account is defined, which the citizen uses and manages along with the institutions he/she considers as more appropriate for himself/herself, according to his/her own criteria.

It is also important to keep improving the way the State and the services deal with citizens. Local experiences of purveyor offices seem to have been successful in solving problems and removing obstacles to social inclusion, allowing that the problems be seen in the perspective of the citizens that actually feel them, and not just according to the perspective of the technical staff to whom they go. This is why dissemination of purveyor services for citizens with disabilities at local level should be disseminated, for relationships with the Local Administration and the decentralised services of the State, and at national level for relationships with the Central State.

Everything converges to the last policy guideline within this strategic goal **to address, in an interactive way, all political, economic, social, educational and cultural inequalities in a decent, open and inclusive society which acknowledges values and celebrates diversity as a positive value**. This goal includes elimination of mechanisms through which differences become transformed into inequalities which generate social discrimination, by promoting the idea that there is a human condition which is common and superior to any expressions of any differences between individuals, including differences resulting from disabilities (Table 50).

(17) Notice, just as an example, that the British Government had a blind minister, for one full decade, that took up one of the most important portfolios (including education, employment and internal affairs), and that the present German Government has a minister, also for internal affairs, who moves around in a wheel chair, and both are politicians of great prominence at national level in their countries.

TABLE 50. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO ADDRESS, IN AN INTERACTIVE WAY, ALL POLITICAL, ECONOMIC, SOCIAL, EDUCATIONAL AND CULTURAL INEQUALITIES IN A DECENT, OPEN AND INCLUSIVE SOCIETY WHICH ACKNOWLEDGES, VALUES AND CELEBRATES DIVERSITY AS A POSITIVE VALUE

Policy guideline		<i>To address, in an interactive way, all political, economic, social, educational, and cultural inequalities in a decent, open and inclusive society which acknowledges, values and celebrates diversity as a positive value</i>
Nature of actions to be developed		Actions oriented towards the elimination of mechanisms through which differences become transformed into inequalities which generate social discrimination, by promoting the idea that there is a human condition which is common and superior to any expressions of any differences between individuals, including differences resulting from disabilities.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To promote inclusive design of products and services, thus increasing the level of participation in collective life, namely by creating a centre of excellence for universal design, and by promoting the dissemination of rules and standards for inclusive design of reference, thus fomenting a culture of enrichment and acceptance of differences, through openness and through the participation of difference. (Domain of acceptance and respect, and of accessibility in terms of communications and programmes)</p> <p>To make life easier for people with disabilities in their communities, namely by guaranteeing housing adapted to their needs at affordable costs, which may imply launching new initiatives for housing at controlled costs and promoting subsidised rents. (Domain of housing)</p>
	Development of competencies	<p>To conceive and apply actions, measures and programmes aimed at empowering all different social players that manage diversity, and at acknowledging differences. (Domain of acceptance and respect)</p> <p>To stimulate creativity and artistic expression of citizens with disabilities. (Domain of creativity and emotional expression)</p>
	Transformation of standards and values	<p>In face of disability, to adopt an attitude of defending human rights and ensuring, consequently, the application of proportional sanctions to cases of direct or indirect discrimination. (Domain of legal protection)</p> <p>Articulation with the media, in order to promote solutions of visual and auditive nature for people with disabilities. (Domain of accessibility in terms of communications and programmes)</p>

As examples of measures that may support the fulfilment of this goal, in the domain of creation of opportunities, two measures of different nature were selected: one, according to the perspective that equality is built by measures, that, even if not specifically aimed at citizens with disabilities, also include their needs, in the design and development of products; and the other one, which is specific support for one of the main basic needs for an autonomous life.

In present day societies, technological innovation continuously opens new opportunities, and new products are designed and marketed at very high speed. These products obey different standards, such as safe use for consumers, and could comply with other standards related with respect and acceptance of difference, such as what happens with standards for inclusive design. While not being specifically aimed at a special group of citizens, they may be developed to consider the needs of different groups, including those whose quality of life we intend to improve with the present strategy. Inclusive design of products and services, while not being specifically aimed at citizens with disabilities, but which also serves them, increases *per se* their level of participation in collective life. Within this scope, one of the charismatic measures could be the creation of one or more centres of excellence in universal design, and within the context of policies of innovation, promoting the dissemination of rules and standards of inclusive design.

At the same time that participation of citizens in the benefits of progress should be promoted, one should not forget about the basic needs that have to be ensured. Due to the association which was detected, in different countries, between disabilities and impoverishment, effectiveness of social policies is highly relevant in order to define the status of these citizens. One of the domains which simultaneously promotes autonomy and ensures physical well-being is the access to independent housing. However, this access may become very much hindered due to the effect of architectonic barriers, due to the relationship between income and costs, and the scarcity of specific services for citizens with specific needs. In order to guarantee adapted housing at affordable costs, it may imply launching new housing initiatives at controlled costs, and new mechanisms for promoting subsidised rents, but it is a key example, this one of concern with individual autonomy of each citizen.

However, the greatest obstacle to full inclusion is still the lack of empowerment of the general population, and namely of citizens with roles and responsibilities in the organisation and functioning of society, and of those with roles in education and training, for managing and for acknowledging diversity. So, the adoption of measures of empowerment for different groups, ranging from receptionists in public services to teachers, or from architects to anonymous citizens, should be included in an action plan aimed at equality of condition.

Such plan should bear in mind that valuing differences has to do with acceptance and respect, but also, and very much so, with valuing potentials, that are

not just restricted to participation in the labour market, as has been said, but which imply all spheres of the right to personal realisation. That is why we are including here, as well, and as an example of empowerment, stimulus to creativity and to artistic expression, by introducing that component in education and rehabilitation *curricula* and by acting positively for valuing that dimension of social participation ⁽¹⁸⁾.

At the level of transformation of standards and values, the same criterion of presenting contrasting examples was adopted. Such as, criterion of normative nature foreseeing sanctions for non compliance and another one within the domain of cooperation and encouragement to greater openness towards diversity by important agents of society.

In the normative plan, it is argued that the time has come to start sanctioning, or making effective, sanctions for any direct or indirect discrimination of citizens with disabilities, as they violate fundamental human rights. In the plan of strategic cooperation, articulation with the media is encouraged, in order to promote visual and auditive solutions for people with disabilities. It should be acknowledged that this is a path that has been followed and that information and communication technologies have been decreasing discrimination at this level.

Equality of condition is feasible, even though not likely to be achieved without strong stimulation and without energetic direction from the long term strategy. However, this last issue is connected, not just with the contents of positive actions, but also with the guarantee of mobilising the appropriate means, in an adjusted way, in order to achieve the desired goals. This is why it was understood that these issues should be included in the definition of the strategy, at the same level as the positive measures and actions. It has to do with ensuring, not just a good strategic direction, but also to try to achieve an efficient use of resources, as we shall try to show with the two following strategic goals.

(18) *In this context, it would be interesting to assess the impact on social perception of Trisomy 21 (Down syndrome), following from the participation of a young actress in a recent Brazilian soap-opera, on TV.*

Strategic goal

“To integrate disability issues in policies, programmes and general interventions, complemented by specific programmes, actions and resources, within the framework of an integrated and multi-sectorial political strategy”

This strategic goal gathers the proposals that shall generate the contents for the architecture of the new rehabilitation policies.

One of the greatest changes, already on going, and which we recommend to be analysed in greater depth, is the reversed role of general policies and specific policies. Therefore, for this reason, we recommend that policy guidelines be adopted, in all sectorial domains, so that the measures to be developed at that level may include solutions to specific problems that citizens with disabilities face, along with the other problems, and that specific measures be developed only when they reveal that they are required and in a complementary way to general measures (Table 51).

In order to fulfil this goal, significant transformations of standards and values are required. The perspective of mainstreaming, in other words, preferential mobilisation of structures and general services available in the community, complemented by specialised services, facilitating access to community services and ensuring specialised competencies and resources, implies a movement in the direction of de-institutionalisation and, being demanding, is a way to improve the conditions for inclusive policies.

Mainstreaming is an instrument for promotion and a condition for equality of results, through full participation in general systems, by promoting autonomy and by participation in adjusted contexts. However, it contains risks, because the general systems need to adapt to the new reality. Which implies allocation of resources in order to make them able to include diversity (for instance, in the initial and ongoing training of teachers/trainers/technical staff, in the adaptation of contexts, in allocating specialised relevant resources and instruments).

TABLE 51. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO INTEGRATE DISABILITY ISSUES IN GENERAL POLICIES, COMPLEMENTED BY SPECIFIC ACTIONS

Policy guideline	<i>To integrate disability issues in general policies, complemented by specific actions</i>	
Nature of actions to be developed	Policy guidelines to be adopted in all sectorial domains, so that the measures to be developed at that level may include solutions to specific problems that citizens with disabilities face, along with the other problems, and that specific measures be developed only when they reveal that they are required and in a complementary way to general measures.	
Examples of measures within the scope of enhancement quality of life	Creation of opportunities	<p>To supply services for supporting inclusion and quality of life, as much as possible within general structures, namely of health, education, social welfare and labour, except in cases of high level of specialisation, and establish and reinforce partnerships between regular and specialised resources, avoiding and eliminating duplication of infra-structures and competencies. (Domain of activation of rights)</p> <p>To ensure the availability of specialised services whenever the community resources do not include them yet, as well as to find solutions for satisfying the needs that requires a high degree of specialisation, at an appropriate territorial level. (Domain of activation of rights)</p>
	Development of competencies	<p>To promote the development of general structures and the qualification of their professionals, in order to prepare them for appropriate actions considering the diversity of characteristics of people with disabilities. (Domain of activation of rights)</p> <p>Development of training initiatives and of actions for raising the level of awareness of leaders and professionals in the area of rehabilitation, in order for them to be able to identify the impacts of mainstreaming within the scope of their interventions. (Domain of activation of rights)</p>
	Transformation of standards and values	<p>Integration of principles of mainstreaming and of diversity management in general policies, ensuring the development of qualifications by all players, for their effective implementation. (Domain of activation of rights)</p> <p>To raise awareness among the significant others of people with disabilities, towards the importance of integrating people with disabilities in the network of general resources and to support them in the respective mobilisation. (Domain of autonomy and resilience)</p>

This strategic step has to be very well prepared and solidly executed, in order to avoid the risk of de-structuring specific traditional responses without first endowing the general systems with the conditions and resources for the inclusive strategy. Special services, once re-structured, and with a new philosophy and strategy of action – for supporting and facilitating access to general structures, acting in a complementary way – may not just become a buffer for transition of models, but even evolve into support instruments for the good functioning of the new model.

Changes of values are not just limited to institutional players. Families and other significant others have shown, at times, some reluctance regarding this transition of models, so any insecurity that has been felt has to be worked out, and they have to be sensitised to the importance of integrating people with disabilities in the general network of resources, whenever possible.

This change is a tremendous challenge, also for leaders, for professionals and for technical staff. On the side of the network of general services, one has to invest in the development of a new attitude of managers and in professional qualifications – a particularly sensitive issue in the case of professionals of education and training, of regular structures – in order to prepare them for the appropriate actions, considering the diversity of characteristics of people with disabilities. On the side of the technical staff of the network of specialised resources, one has to promote their reconversion to their new functions.

The new model of intervention which is being proposed implies the guarantee of availability of appropriate services and resources for general structures, namely for health, education, social welfare and labour, which have to be mobilised first, and of covering the needs, except in what concerns cases of high specialisation, which supposes that partnerships be established and reinforced between regular and specialised resources, avoiding and eliminating duplication of infrastructures and competencies.

At times there is the fear of emptying the network of existing services, but what is being proposed is its reconversion for a new mission.

TABLE 52. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO INTEGRATE AND COORDINATE MEASURES AND ACTIONS INTO A COMMON POLITICAL REFERENCE FRAMEWORK, WHILE ENHANCING SECTORIAL RESPONSIBILITIES

Policy guideline		<i>To integrate and coordinate measures and actions into a common political reference framework, while enhancing sectorial responsibilities</i>
Nature of actions to be developed		Necessary procedures so that the diversity of measures and actions may follow a common rationality, may contribute towards the defined goals, and may be executed under the responsibility of defined entities.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To promote the coordination, at territorial level, of services provided to the citizens, through the development of a network of centres for supporting inclusion for reception, support and follow-up, integrating and facilitating access to available resources and services, in a logic of case management. (Domain of activation of rights).</p> <p>To establish a correspondence between services offered and allocation of resources, and needs and geographical distribution of people with disabilities. (Domain of activation of rights)</p>
	Development of competencies	<p>To act with the purpose of increasing the qualifications of people with disabilities, in order to enhance their autonomy and mobility, and to facilitate their access to the resources that society disposes at all different domains. (Domain of autonomy and resilience)</p> <p>To train managers and professionals of the inclusion support centres, in order for them to act according to a logics of ongoing support to the definition and management of individual pathways of inclusion/reintegration. (Domain of activation of rights)</p>
	Transformation of standards and values	<p>To ensure trans-sectorial coordination of policies made by a specific governmental instance, responsible for a global action plan. (Domain of activation of rights).</p> <p>To develop sectorial action plans at the level of the different ministries with responsibilities and competencies in this domain. (Domain of activation of rights)</p>

So that the new model for organising provision of services works properly, opportunities for inclusion have to keep being continuously created, and pathways have to keep being supported within the logic of life cycle, through structures with specific competencies and resources for such purpose. In articulation with the existing general resources, it is important that, starting off from the already installed capacity, a specialised capacity of response be structured in order to receive, support and then follow-up, that may facilitate access to services, which should be available, in appropriate economic conditions, accessible and with quality.

These support centres should work as one stop shops, for information and counselling, for supporting diagnosis and for assessing individual needs, for supporting the preparation of individual habilitation/rehabilitation plans, for supporting citizens and their significant others in managing life pathways, mobilising and networking with structures and sectorial resources. In other words, these are structures with territorial basis which constitute a critical instrument for supporting the articulation between programmes and measures, and for facilitating the transition between different stages of the life cycle, operationalising the case management approach.

Within the demanding framework of scarce resources, one has to plan the network of specialised centres, by decreasing the distance between the “geography of initiative” and the “geography of needs”. As a matter of fact, considering the solidary basis of the existing network of resources, it was born from local dynamics and protagonisms that generate situations of potential incoherence and overlapping, such as the maintenance of areas where, in spite of the fact that problems do exist, no initiatives appeared to cover them.

In the same logics of the Social Charter, it is very important that resource planning starts from a deep understanding of problems and needs, and from the definition of the respective solutions; that desirable coverage rates be defined in order to assess the amounts of resources needed and to decide, at that level, network rationalisation and optimisation, in order to achieve universal coverage, avoiding duplications, overlapping and redundancies.

Thus, new opportunities for enhancement of citizens are created, which implies an effort of empowerment so that these opportunities may be transformed into results, which makes that, specially specialised resource centres, must act in a way as to improve the levels of autonomy and mobility of citizens, and to facilitate their access to the types of resources available to society at all different domains.

In order to achieve such goal, a great effort of institutional empowerment is required, namely in terms of training managers and professionals of the present specialised resources, in order to prepare the paradigm shift of resource centres, working in a logics of ongoing support, to the definition and management of individual paths of inclusion.

The need for institutional empowerment extends to the coordination of policies and measures itself. The appropriate preparation of the new model, in order for its effectiveness to be maximised, requires a specific governmental instance which should be endowed with a strong mandate and with authority over public and sectorial services, which may ensure trans-sectorial policy coordination.

This specific instance needs to have clearly defined competencies, and should be entrusted with the responsibilities of executing a global action plan and monitoring the sectorial action plans for the different sectors with competencies and responsibilities in service provision, care or support. These sectorial plans, just as the global plan, should be prepared and applied with the guarantee that people with disabilities were actually consulted, containing information on codes of practice, regulations, monitoring and review procedures, and periodical progress reports.

Having the framework of responsibilities well defined (which shall be dealt with further ahead, when dealing with the governance model), it is important to consider the nature of the services being provided. These citizens, as clients of a given service, are not different from any others. They are clients with rights, with needs and expectations that need to be fulfilled with quality. Commitment with this approach is just another critical point for the paradigm shift in the relationship with citizens, and so it is argued that measures for regulating specific services provided specifically to citizens with disabilities be adopted, so that the conditions for providing these services come as close as possible to those stipulated for general social services (Table 53).

Coordination among sectorial interventions is fundamental, in order to achieve effectiveness in these services. During transition between services, when improperly done, often citizens are “lost” and many others are discouraged from following paths of inclusion, or else disturbance factors are created for individuals and their families that create obstacles for the inclusion processes.

The strategy proposed herein implies that the actions to be undertaken consider the citizen as a whole, and experience has shown that this is the most appropriate way of moving from measures predominantly of assistencialist nature to emancipatory measures, that may materialise transformations in social status, based on personalised reception and mobilisation of partnerships among the different players.

TABLE 53. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO CONCEIVE ALL DISABILITY-RELATED SERVICES AS AN AREA OF GENERAL SOCIAL SERVICES

Policy guideline		<i>To conceive all disability-related services as an area of general social services</i>
Nature of actions to be developed		To adopt measures for regulating specific services provided specifically to citizens with disabilities, so that the conditions for providing these services come as close as possible to those stipulated for general social services.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To ensure the continuum of services centred on people, coordinated and based on the community. (Domain of rights)</p> <p>To universally ensure the dimension of follow-up to former clients in order to assess the effectiveness of interventions and, if required, to promote repairing actions that may improve results (All domains where enhancing citizens' quality of life can be improved)</p>
	Development of competencies	<p>To acknowledge that citizens are capable of identifying their own needs, and offer them opportunities for developing such competencies. (Domain of psychological development and social capacities)</p> <p>To promote the inclusion of the topic of disabilities in curricula for training professionals of social services. (Domain of activation of rights)</p>
	Transformation of standards and values	<p>To create a total quality management system based on principles such as participation of addressees and remaining stakeholders in programmes and measures. (Domain of acceptance and respect)</p> <p>To foment the market of social disability-related services and of support to dependence. (Domain of activation of rights)</p>

As mentioned above, someone's needs are global and have an integrated nature, and so they should be provided for also in an integrated way, ensuring coherence of the services provided. Now, how to do it? By ensuring the continuum of services, centred on the person, coordinated and based on the community, while including in that continuum of services, post monitoring of results achieved, in order to assess the effectiveness of interventions and, if required, to promote repairing actions that may improve results. In other words, service

to these citizens, as to any other citizens, is not concluded when provided, but rather when the desired effect is produced or the expected result is achieved.

The understanding of the paradigms of the past was that these services were skilful: only the technical staff knew the needs of “patients”. However, history is showing the opposite, namely acknowledging that people with disabilities are capable of identifying their own needs, and that they can be helped in order to develop such competencies. Actually, doing so is an important stage in the process of rehabilitation and of social inclusion, and a way of decreasing citizens’ dependence. Care and service providers should try to integrate interventions according to needs and, at the same time, recognise, stimulate and mobilise the capacity that citizens have to identify their own needs.

By intending to move swiftly in that direction there are obstacles to face, namely in terms of scarcity of professionals with appropriate training within the scope of disabilities, and so one of the priorities mentioned in this example of measures is to reinforce training in this domain, not just for professionals of technical rehabilitation areas, but of all social service professionals. To also train these professionals in the relationships with the citizens with whom they work, is an important element of the orientation towards improved quality of life, in opposition to the type of training exclusively oriented towards technical procedures.

The ultimate goal of such re-orientation is improving quality of services. Now, in several domains of activity, this was done by adopting internationally recognised and well identified quality reference systems. The same can and should happen in this domain, just as in other social services. However, with the understanding that the value of recognition and participation of stakeholders is an obligatory part of the quality standards to be adopted, due to the nature of the service.

In this way, service provision is generically connected to the challenges of social policies. Should we search for a model of policies for disabilities or should we intervene in a model of social policies which includes the issue? This is not exactly the place to define and analyse in depth the varieties of modern Welfare States (please refer to GOSTA ESPING-ANDERSEN, 1990, 1999). However, social policies with specificities for disabilities need to be designed, which are not neutral from the point of view of re-orientations of the Welfare State.

Recent trends point towards the development of the welfare-mix and the recalibration of all varieties of social model (cf., for example, FERRERA ET AL., 2000). It is unavoidable to combine the three pillars of such mix: Family, State and Market.

In Portugal, there is a historical legacy in which the market connected to services in the area of disabilities is residual. That is why the example is given of the change that needs to be made in terms of thinking and regulating such

market. As was seen in terms of international trends, some countries have radically followed that path, and are presently facing problems that can be avoided by learning from their lessons, namely, that the most serious problems are those covered by operators with less quality and that the starting inequalities get reflected in the access to services. The global action plan to be developed shall have to consider very well the balance between the role to be fulfilled by the State, by the sector of solidarity and by the development of a market of social services also in this domain.

Strategic goal

To grant greater efficiency and greater accountability to policies and measures, within the framework of a demanding management culture, with the participation of all citizens and social players involved, while ensuring high levels of quality for services and in the production of responses to needs”

This strategic goal defines a new platform of demand, in terms of transparency and accountability of the State before the citizens and before the representative organisations. The first policy guideline proposed at this level has to do with creating new conditions of accountability for policies, programmes and interventions, by defining goals and targets which can be appropriately checked and monitored, by introducing mechanisms for planning measures, and policies that guarantee clear goals to be achieved, and monitoring and assessment of results and impacts (Table 54).

The first condition in order to solve any problem is to know it properly. However, Portugal still does not have, in its national system of statistics, indicators on the phenomenon of disabilities. As argued above, and as experienced along this study, the ICF enables to capture properly the extension and forms of this phenomenon. In order to act properly, it is fundamental to dispose of knowledge adjusted to the reality upon which one is operating. That is why we are insisting on the need to perfect the national system of statistics so that it may be useful for the formulation of policies and so that it may supply reliable and regular information on something which is reaching a significant proportion in our society.

Monitoring the model which was proposed also implies the development of a system of indicators that can cover the diversity of domains of quality of life. Only in that way can we have the opportunity to properly define priorities, and to re-orient the direction of actions whenever necessary. Such indicators should

be able to measure the perception of subjective well-being, and to carry out structural improvements in enhancing the quality of life.

TABLE 54. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO CREATE NEW CONDITIONS OF ACCOUNTABILITY FOR POLICIES, PROGRAMMES AND INTERVENTIONS, BY DEFINING GOALS AND TARGETS THAT CAN BE APPROPRIATELY CHECKED AND MONITORED

Policy guideline		<i>To create new conditions of accountability for policies, programmes and interventions, by defining goals and targets that can be appropriately checked and monitored</i>
Nature of actions to be developed		Mechanisms for planning measures and policies that guarantees clear goals to be achieved, and monitoring and assessment of results and impacts.
Examples of measures scope of enhancement of quality of life	Creation of opportunities within the	To introduce, in the national system of statistics, an indicator for disabilities, considering the ICF as the reference system. (Transversal measure) Creation of a regular device for collecting reliable and appropriate information on the quality of life of people with disabilities. (Transversal measure)
	Development of competencies	To promote research on the social condition of citizens with disabilities. (Transversal measure) To give training to technical staff for operationalising the model of quality of life and for monitoring progress in the lives of citizens. (Transversal measure)
	Transformation of standards and values	To promote regular monitoring of performance indicators of policies for enhancing the quality of life of people with disabilities, with the purpose of raising awareness towards the deficits of quality of life of these citizens and giving greater visibility to their problems. (Transversal measure) To promote the issue of equality of condition of these citizens as a relevant political issue, central for actions within the social scope, by publishing an yearly report, to be submitted to the Council of Ministers, and for public discussion. (Domain of solidarity)

The present situation with many dispersed studies and scarcity of reliable data is a factor of increased difficulty for conceptualising a coherent strategy for action. The knowledge gap may be overcome through investment in researching the social condition of citizens with disabilities, and by training a team for monitoring their progress in terms of their quality of life. There are already some experiences in Portugal of works of micro assessment of such progress, but it is fully justifiable to promote a consistent macro assessment methodology as well as training of researchers and technical staff to develop it.

Regular monitoring of performance indicators of policies for enhancing the quality of life of people with disabilities, will contribute to a greater awareness of the deficits of quality of life of these citizens, and will offer greater visibility to their problems. Such task implies not just designing the indicators, collecting, coordinating and systematising the data, but also ensuring their accessibility to society at large, in understandable formats, and promoting participation in their discussion by the citizens directly affected, as well as by larger groups of citizens.

The issue of reduced visibility of the problems is part of the problem itself. One of the required changes of attitude, in order to achieve greater accountability for the policies being implemented, is to maximise public visibility of the issues faced by these citizens and involvement at the highest institutional level, in ensuring that appropriate measures are taken and that results are wanted. To withdraw these policies from the situation of semi-obscurity in which they have been and to change the perspective that this policy is a peripheral concern, is something that can be achieved by creating an yearly occasion for debating the progress made and the obstacles that were faced, for instance, with a report to be submitted to the Council of Ministers, and through public discussion. Actually, such measure would be an example of how can the next policy guideline function in order ***to adopt transparent and participatory design, management and evaluation systems, in which the different stakeholders are co-accountable and where their active participation is encouraged*** (Table 55).

TABLE 55. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO ADOPT TRANSPARENT AND PARTICIPATORY DESIGN, MANAGEMENT AND ASSESSMENT SYSTEMS, IN WHICH THE DIFFERENT STAKEHOLDERS ARE CO-ACCOUNTABLE AND WHERE THEIR ACTIVE PARTICIPATION IS ENCOURAGED

Policy guideline		<i>To adopt transparent and participatory design, management and assessment systems, in which the different stakeholders are co-accountable and where their active participation is encouraged</i>
Nature of actions to be developed		<p>Follow-up devices and devices for evaluating the execution of measures and policies, complying with the principles of:</p> <ul style="list-style-type: none"> • Transparency: that generate known results, and disseminated by all relevant partners; • Participation: conceived and executed with the involvement of relevant partners.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To prepare the action plans that materialise the Strategy for Enhancing the Quality of Life of Citizens with Disabilities based on the diagnosis of needs of the citizens and their families, establishing expected goals and results, impacts to be achieved, schedule of development, definition of responsibilities and monitoring and assessment mechanisms. (Transversal measure)</p> <p>To promote the widest possible participation, namely by granting legal and/or formal capacity to citizens with disabilities, to their legal representatives and to representative institutions, for participating in decision making instances. (Domain of activation of rights)</p>
	Development of competencies	<p>To encourage citizens with disabilities to take part in decision-making processes regarding policies, measures and services, while offering them appropriate training for such functions and responsibilities. (Domain of performing roles and functions in public life)</p> <p>To support institutional empowerment of representative organisations, so that they may carry out advocacy for citizens with disabilities. (Domain of performing roles and functions in public life)</p>
	Transformation of standards and values	<p>To reinforce the advisory role and the role of issuing opinions, of people with disabilities and their representatives, in decision making processes. (Domain of acceptance and respect)</p> <p>To create routines of communication that may enable access to results by all citizens, thus improving familiarity of public opinion with these issues. (Domain of acceptance and respect)</p>

Evaluation is often considered as something instrumental, but the feedback effects from well performed evaluations upon planning of new measures and improvement of existing ones is a factor of effectiveness of interventions. However, in order for measures to be evaluated, their design has to comply with that orientation, by being designed and formulated with that purpose.

In this Study we present a conceptual model for a strategy, upon which a Strategy for Enhancing the Quality of Life of Citizens with Disabilities may be based, should that be the will of the actors of the System. Such would imply the development of this exercise, its appropriation by the system of actors and the development of a set of activities that will lead to the preparation of action plans, based on diagnosis of needs of citizens and their families, and on establishing expected goals and results, impacts to achieve, schedule of development, definition of responsibilities and, monitoring and evaluating mechanisms.

Adoption of that strategy shall place Portugal next to the most advanced countries in this domain. And by ensuring as well participation of citizens with disabilities and their legal representatives and representative institutions, at all moments, in decision making instances, from design to assessment, namely by endowing them with legal and/or formal capacity, Portugal may be placed next to the most recent trends of development of international policies.

With the starting picture as identified in our empirical research, that goal can only be achieved with the adoption of training measures and measures of encouragement of citizens to take part in the decision making processes and in management, planning and evaluation of services provided. However, such effort would be in vain if it were not accompanied by a significant change at the level of the real power of citizens in relation to service providers, with the reinforcement of consultation and of opinions issued by people with disabilities and their representatives within the decision making processes.

This path shall be facilitated by the existence of strong representative organisations that may exercise advocacy of citizens before service providers, among others. Such institutional empowerment needs to be searched for, and developed by the organisations themselves, as their responsibility, as a condition for fulfilling their mission, and should also be encouraged by the State, as one of the pillars upon which is based the change of perception of these services, as solidary support, for them to be perceived as responses to social rights. Another one is the creation of routines of communication that may enable access to results by all citizens, thus improving familiarity of public opinion with these issues. Mobilisation of public opinion is an instrument and a factor of development of news responses and of appropriate policies, which makes it into one of the most important resources of social policies in contemporary mediatic democracies.

TABLE 56. NATURE OF ACTIONS AND EXAMPLES OF MEASURES FOR ENHANCING THE QUALITY OF LIFE WITHIN THE SCOPE OF POLICY GUIDELINE TO RECONCILE EQUITY AND EFFICIENCY IN MANAGEMENT, PROMOTING QUALITY OF SERVICES AND RESPONSES OFFERED TO CITIZENS

Policy guideline		<i>To reconcile equity and efficiency in management, promoting quality of services and responses offered to citizens</i>
Nature of actions to be developed		Procedures for regulating management of services provided to citizens with disabilities, which may promote fair conditions of accessibility to quality services, while managing resources in an efficient way.
Examples of measures within the scope of enhancement of quality of life	Creation of opportunities	<p>To create mechanisms for accreditation of entities that provide services to citizens with disabilities and for certifying such services, in charge of the national agency responsible for coordinating the rehabilitation policy, involving a National Quality Committee with the participation of representatives from stakeholders. (Transversal measure)</p> <p>To support the modernisation and improved quality of services provided by adopting specific incentives and support. (Transversal measure)</p>
	Development of competencies	<p>To promote the development of the capacity to make choices and to take decisions by people with disabilities and significant others followed by counselling services and by orientation towards quality, leveraging the use of available resources by citizens. (Domain of accessibility in terms of communications and programmes)</p> <p>To develop monitoring and evaluating methodologies, as far as the effectiveness of actions at all levels, in order to disseminate good practices and to empower the system for improved performance. (Transversal measure)</p>
	Transformation of standards and values	<p>To adopt a management strategy for the rehabilitation system based on holding pluri-annual programme contracts, indexing funding to goals, results and impacts to be achieved, and establishing criteria for assessing the respective quality. (Transversal measure)</p> <p>To define guidelines for preparing codes of conduct for the organisations delivering social services to citizens with disabilities, whether or not such organisations are specialised in such services. (Transversal measure)</p>

In order to proceed towards rationalising the network of service provision, an important part is still missing – a system for accreditation of entities – that should evolve from a pedagogical and counselling stage, to a stage of periodical evaluation of compliance of performance standards. This process will be facilitated by the development, at short term, of guidelines for preparing codes of conduct for organisations delivering social services to citizens with disabilities, whether or not such organisations are specialised in such services, and by adopting specific incentives and support. For such purpose, it would be useful to create a system of quality assurance, through accreditation of the intervening entities before the national agency responsible for coordinating the rehabilitation policy, associated to a quality committee for rehabilitation services with enlarged participation.

One must bear in mind that the rationality of the network of care and service provision is not self-evident, not for society in general, nor for its potential users in particular. Access of citizens to quality counselling and guidance is important so that they may make their choices and decide on how to resort to the existing services, as in this matter only that which is known is real.

Such counselling has to start from the evaluation of which intervention generates which result, and this implies the development and use of evaluation methodologies at micro scale regarding the effectiveness of the initiatives, in order to disseminate good practices and to empower the system for improved performances, as well as to offer citizens appropriate information on the expected results from the services they access.

Once these indicators have been defined and monitored, the exercise of defining goals and targets to be achieved and platforms of service quality become much more clear and precise, which enable another structural change in the system of actors of rehabilitation: to start basing the management of the rehabilitation system in pluri-annual programme contracts, indexing funding to goals, results and impacts to be achieved, and establishing criteria for assessing the respective quality.

Tension between quantity and quality in service provision is real, and the expansion and reconversion of any network always contains the risk of quality losses.

Quality assurance has to be introduced in the development of the system, and one of such guarantees is the creation of devices to increase *openness and transparency* and to leverage independent assessment, as happens with *tendering and application* mechanisms, *permanent performance monitoring and evaluation* – of programmes, institutions, players – or *instruments to encourage quality*, by valorising and rewarding it.

A path that can be followed is to access such programme contracts through tenders ⁽¹⁹⁾ complying with certain basic principles, out of which we would highlight the following:

- **Transparency:** all the rules used in determining the volume of funds, all the control mechanisms to be used, as well as the definition of eligibility of expenses, should all be previously known by all those intervening.
- **Clarity:** the variables used for the calculations of funding, as well as the formulas in which such variables take part, should be fully clarified.
- **Simplicity:** the funding process should be as simple as possible, with no difficult entanglements to overcome, so that all energies used in this component of the project may be reduced.

Evolution in this direction implies that guarantees of security are given to all stakeholders, organisations and their representatives, to the State and to its agents, to funding entities and to other participants, in an environment of trust, which is fundamental so that the intervention of each agent in the system is developed in conditions of normality. Funding from any service provider has the purpose of helping to create the conditions to achieve the goals that were proposed. Besides relationships of trust among all different intervening parties, it is very important that conditions of stability are created in the system, so that throughout the years any surprises are avoided which may affect the activities of training institutions, and consequently their results.

In summary, once these issues have been properly equated, we may advance towards a new framework of funding, which would have the advantage of bringing to a similar level operators of different types and be guided by the final goals of the strategy model being proposed: to offer better quality of life, and to ensure the equality of condition to citizens with disabilities by 2025.

(19) A similar procedure to the one presented herein was recently proposed, within the scope of expansion of the professionally qualifying offer (CF. PEDROSO ET AL., 2007).



Chapter 9.
**The governance model
of Strategy**

GOVERNANCE

– A DECISIVE FACTOR FOR A SUCCESSFUL STRATEGY

As in any strategy, of any nature, issues related to its implementation, to the organisation of the different dynamics for its operationalisation, the issues related to appointing responsibilities, to monitoring and controlling progress in its implementation, assessment of results and impacts which were achieved, are all decisive factors for its success. Besides the own merit of the guiding principles themselves, of the pertinence and fairness of the proposals and action goals, of the coherence and pertinence of the working models proposed, the success of any political strategy is also strongly dependent on the ways of organising, monitoring and assessing its implementation.

Presently, social services are a developing sector, facing critical challenges for its modernisation and for developing quality, within a framework of scarce resources, and so it becomes absolutely necessary to reconcile, in a virtuous way, universality of social responses, quality, and sustainable services. Thus, these circumstances endow all issues related to the governance model with a decisive relevance and importance, implying a new approach and a different way of enhancing the issue, in face of the common practices for managing social policies.

In this respect, policy and strategy guiding documents that have been formulated by international instances – of the European Union and others – address the issue as a key issue for successful policies, and uphold it as a political imperative, with guiding nature, or at times even with regulating nature. Just as an example, and just for its specificity, the **Declaration made by the Disability High Level Group of the European Union, on the Quality of Social Services of General Interest** (2007) states that one of the regulatory principles for service quality is “*Good Governance: openness, participation, transparency, efficiency and accountability are to be applied by all types of organisations delivering social services to people with disabilities.*”

Criteria: definition of principles and values at stake in service delivery; definition of the responsibilities and interrelations of the actors who manage, design, deliver, support and evaluate service provision; annual planning and review process with participation of staff in the definition and evaluation of roles and responsibilities of the various functions at stake in service delivery; cooperation with other agencies involved in the continuum of services to facilitate access to a comprehensive range services; records on outcomes of individual service plans and continuous evaluation of person served satisfaction; accessible complaint procedures; collection of feedback from purchases, funders and other stakeholders on performance; formal periodic and independent review of the business results of service providers.”

On the other hand, this Declaration takes up a set of assumptions considered

as fundamental for framing and developing social services related to disabilities, aligned with the pillars of modernisation proposed by the Communication from the European Commission, dated from April 2006, related with Social Services of General Interest:

- *“the introduction of benchmarking methods, quality assurance, and the involvement of users in administration;*
- *decentralisation of the organisation of these services to local or regional level;*
- *the outsourcing of public sector tasks to the private sector, with the public authorities becoming regulators, guardians of regulated competition and effective organisation at national, local or regional level;*
- *the development of public-private partnerships, and use of other forms of funding to complement public funding.”*

And so the above mentioned principles would just become reference systems for guiding the EU Member-States, with differentiated perspectives and dynamics over some dates, orientations, and so it is pertinent to consider them as development trends, with political reference systems, within a modelling context such as the present one.

As a complex and comprehensive dynamics, the issue of **governance** of the strategy for enhancing the quality of life for people with disabilities is structured around some fundamental **guiding principles**.

- To integrate disabilities issues in general and transversal policies, and to integrate sectorial policies, programmes and measures, in global policies and strategies.
- To plan political action in order to ensure implementation of the strategy, integrating it in general plans, complemented by specific sectorial plans, in the relevant political domains for enhancing the quality of life.
- Social dialogue as a fundamental lever for any successful strategy, promoting mobilisation and the adhesion of different social players, with special emphasis for employers.
- Involvement and co-accountability of all players involved, namely of citizens with disabilities and their significant others, through mechanisms of effective consultation and through participation of all stakeholders, in an open, responsible and committed way, mobilising and activating them, in a logic of parity partnership.
- To delegate responsibilities and competencies, within a context of decentralisation, with diverse and complementary instances, at national, regional and local levels.
- Clear definition of responsibilities at all levels of the System – of nation-

al policy, of sectorial policies, of national instances, sectorial, regional and local, of service providers, of the citizens and their families, of other social players, within a framework of shared responsibilities.

- Commitment with orientation towards results, through the establishment of goals and targets to achieve, of indicators of execution, and of the respective monitoring methods, for all planning instruments, at all levels of action.
- Effective and acting coordination, at political, strategic and operational levels, framing the different instances of the System with actual regulatory capacity upon the design, implementation, management and evaluation of the policy and of its impacts, through:
 - › Defining strategic goals and objectives to be achieved, transposing national goals to policy sectors, to regional and local plans, indexed to timed periods;
 - › Establishing quantitative and qualitative indicators for monitoring and assessment;
 - › Promoting cooperation, benchmarking and sharing successful practices.
- Monitoring and evaluation as fundamental activities, at the level of political strategy, of planning – national and sectorial –, of programmes and measures, and of interventions, assessing performance and the players involved, guided by reference systems and quality criteria, instituted as general and transversal references.

LEVELS AND DYNAMICS OF COORDINATION

One of the corner stones of the Strategy, which is being presented as an integrated political strategy, is based on the fundamental principle of indispensability of adopting cooperation models, for practical action, integrating and articulating the different sectors, institutions and social responses, ensuring integrated systems of intervention, centred on citizens and on their needs. Thus, the underlying governance model should also adopt an integrated and coordinating approach, ensuring a coherent, synergic, aligned and harmonised implementation, at the risk of not being ensured the global and integrated solutions which are required, resulting from the coordinated and coherent action among the set of different players.

Integration and coordination are thus the key dynamics of governance, as a fundamental condition for a successful Strategy.

In terms of architecture of the governance system, a key issue is the structure and scope of responsibilities, with three structural instances.

- Policy and strategy design and coordination, of the responsibility of the government instance, with transversal and trans-sectorial scope.
- Coordination, monitoring and evaluation of the policy operationalisation, including quality evaluation of social responses and of services provided to citizens, of the responsibility of a national agency under the control of the government instance.
- Implementation of sectorial policies that materialise the policy, of the responsibility of sectorial governmental agencies.
- Operationalisation of programmes and measures, translated into services for the citizens, of the responsibility of:
 - > Regional instances, in the case of actions that require and serve a larger basic population;
 - > Local instances, for the proximity of services.

In terms of governance, the issue of information on the work domain, of its quality and actuality, and permanent monitoring of the system, are decisive vectors, fundamental conditions for success. It is not possible to govern something well if it is not known in depth, or if not enough updated, pertinent and reliable information is available. So, the challenge is thus to have permanent, systematised and updated information on disabilities, as well as on the performance of the policy and of the policies, of the System, of the programmes and measures and of service providers.

The dynamics of an observatory of disability in Portugal would be guided by a set of fundamental guidelines, in order to generate the above mentioned results.

- Stabilisation of concepts and structural definitions by creating unambiguousness and transparency of information and communication.
- Use of the ICF as an analytical reference system.
- Integration and follow-up of all studies and research carried out in Portugal and in other contexts, optimising knowledge management and leveraging its impacts.
- Regular generation of statistical data enabling constant update of such data, namely by integrating statistics on disability in the national statistical system.

- Implementation of an information system collecting, treating and making available statistical indicators and other indicators – related with the phenomenon and with performances, as well as providing useful information to all different players.
- Implementation of monitoring processes and dynamics, in a structured and systematic way, in order to follow the execution of the strategy and of the national plan, of the sectorial plans, and of the programmes and interventions, assessing policy and strategy results, assessing programmes and measures and their appropriateness, and promoting their update in an ongoing way.

Coordination instances

- Member of the Government with transversal competencies for designing and coordinating national policies and strategies, and for high level coordination of the respective implementation.
- National agency responsible for:
 - > coordinating policy operationalisation, monitoring and assessment, in articulation with the responsible Government member;
 - > implementing the dynamics of an observatory of disability;
 - > generating strategic reflection and knowledge production;
 - > fomenting more modern social responses as well as from intervening social organisations, aiming at ongoing development of their empowerment;
 - > instituting reference systems as well as systems for ensuring and regulating a quality service, in articulation with sectorial agencies and with representative organisations, coordinating the operation and functioning of such system.
- National Council for rehabilitation of people with disabilities, superior instance of participation of all stakeholders and of all parties involved in designing, operating, monitoring and evaluating the national policy and strategy, with actual capacity to influence decision making, through competencies assigned by statutes and acknowledged social credibility.
- Authority for promoting equal opportunities and non-discrimination – entity responsible for formulating, monitoring and updating the po-

litical and juridical framework related to equal opportunities and non-discrimination of people with disabilities, as well as for analysing and deciding on situations of non compliance of principles and of legal instruments for equal opportunities and non-discrimination.

- Regional/local councils for inclusion of people with disabilities – instances for participation of stakeholders, with restricted territorial scope, of proximity nature, with competencies for supporting the organisation and planning of responses in the respective area of influence, for monitoring and assessing the results achieved.

From the articulated and coherent intervention of the above mentioned instances, the result will be an effective and participated policy governance, within a framework of searching for the highest levels of adequacy to the needs and expectations of citizens, and highest levels of involvement and commitment from the different intervening parties, guided by a common political reference system: to promote more and better quality of life for people with disabilities.

QUALITY CHALLENGES

Issues related with modernisation and quality are at present a central concern in all documents of the European Union which, to some extent, materialise the policy options in terms of social services, including social disability-related services, considered as social services of general interest.

Besides these, there are other international instances that also place the issue of quality as a central and structural concern of their strategic guidelines and as an imperative of the different intervening parties.

Therefore, within the context of formulating a Strategy for Enhancing the Quality of Life of People with Disabilities, the issues of quality of responses and quality of services, of the dynamics of their promotion and regulation, justify a specific approach in order to clarify the regulatory model as well as its assumptions, guiding and mobilising promotion of service quality and of the responses to the specific needs of citizens, as a complement to those ensured by general services.

Quality, as satisfaction of needs and expectations of clients – determined and assessed by them – with efficient consumption of resources, seems like something that has to do not just with clients, but with all stakeholders in general, becoming as if a fundamental reference system for decision making by the different players involved, taking up a central role in any governance model.

As a vast, comprehensive, integrating and dynamic concept, quality refers to several dimensions:

- quality of life;
- quality of policies;
- quality of social services, of social responses;
- quality of system management;
- quality of organisations;
- quality of services provided;
- quality of professionals;
- quality of methodologies and instruments;
- quality of results and impacts.

Due to its relevance and central nature, **quality** is thus a **working challenge** at system level, fundamental for ensuring:

- the adequacy of policies and of responses to needs and expectations of citizens;
- the coherence, convergence, synergy and strategic alignment of programmes, measures and responses;
- the effectiveness of policies and responses, and maximum resource value, through an efficient management thereof;
- the satisfaction of all stakeholders;
- the transparency towards the policy and the system.

As a common reference framework for formulating, organising and managing the jurisdiction, within the framework of a socially responsible, committed and demanding partnership, **quality** seems like a fundamental **reference system of action** for key players:

- For the Government and its agencies, as regulating and funding entities, supporting formulation of policies, programmes and measures, allocation of resources, monitoring and evaluation of results and impacts, management of efficiency and effectiveness of all resources involved.
- For citizens and their significant others, promoting their rights, supporting their active participation, enlightened and demanding decision making, and their accountability.
- For intervening organisations – representative organisations and service providers – supporting strategic formulation, organisation of their operational interventions, optimisation of responses they ensure, and of the value they add to the resources they manage.

Quality – social services of general interest

In terms of the different international instances, the issues of modernisation and of quality of social services, both of general ones, and of those related to disabilities, take up a central position in all regulatory documents and in all documents of strategic orientation, with a level of relevance similar to that of the conceptual and ideological issues.

Present as one of the concerns of the UN International Convention on the Rights of Persons with Disabilities (2006), the issue appears recurrently in all documents of reference of the European Parliament, of the Commission of the European Communities, of the Council of Europe and of the CEDEFOP.

The European Union documents related to matters of social services of general interest – thus, also those related to disabilities – identify a set of new dynamics and policy trends that configure **challenges to national players** in terms of **service design and organisation**:

- Greater difficulty to access public funds, in face of the available resources.
- Introduction of dynamics of greater competitiveness, resulting from the principle of internal market and from the rules of competition, also gradually applicable to social services, and with possible impacts in disability-related services.
- Deep change in the ways the State contracts service provision, with increased competitiveness among service providers.

- Introduction of reference systems and systems of quality certification and quality assurance.
- Demand for demonstrating the added value by service providers, in terms of performance, and of compliance with quality and price requirements.
- Emergence of dynamics of service provision of multinational nature, mobilising frameworks of trans-national cooperation.

Within this scope, the Declaration made by the Disability High Level Group of the European Union, on the Quality of Social Services of General Interest (2007), following the concerns of the European Commission on the quality of social services, as well as the European Action Plan for Disability, by the European Commission (2006), which defines as a priority the issue of service quality, declares and recommends the following guiding principles for enhancing the quality, to be implemented in a specific way by the national contexts:

- Need for a European quality reference system, guided by the total quality model, based on values, principles and criteria of reference.
- Implementation of such European quality reference system in the Member-States, according to the diversity and specificity of each country.
- Focusing the quality systems in promoting and acknowledging continuous improvement, stimulating improved performance of service providers, in terms of efficacy and efficiency.
- To mobilise those countries where service quality is less developed, encouraging the adoption of quality management systems and practices.

With the aim of fulfilling the above mentioned goals, the recommendation presents a set of common principles and criteria of reference, to be applied in the different Member-States according to their own contexts and specificities, while respecting the principle of pension. It recommends the need for quality indicators, of quantitative and qualitative nature, enabling quality evaluation of the services provided, and of their results and impacts.

Common principles of reference for managing quality of social disability-related services, as proposed by the Declaration

Rights

Choice, freedom of choice (including personal choice on how services are individually delivered), self determination, non discrimination, including recognition of the position of women with disabilities within service planning and delivery.

Person centred

Social services of general interest for people with disabilities should tackle the needs of each individual with the aim to enhance the quality of life and equality of opportunities of the persons concerned. In line with the social model of disability, the physical and social environment of the person served should be taken into account.

Comprehensiveness and continuity

The continuum of holistic services – from early interventions to support and follow up- involves multi-disciplinary actions and coordination. Furthermore, such a continuum is essential all along the life of persons with disabilities, therefore a life cycle approach is to be taken. The life cycle stages are: children with disabilities, people with disabilities of working age, older people with disabilities.

Participation

Users, first and foremost people with disabilities themselves, should be actively involved in the service team and engaged in self assessment and feedback.

Partnerships

All potential partners, including employers, the local community, social partners, funding authorities, policy makers are to be involved alongside service providers.

Result oriented

Quality is directly related to outcomes for the user, measuring satisfaction is crucial. Quality outcomes areas are to be identified by all stakeholders and used as reference to assess the success of the service in meeting individual needs.

Good governance

Openness, participation, transparency, efficiency and accountability are to be applied by all types of organisations delivering social services to people with disabilities.

In the recent Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions, entitled “Services of general interest, including social services of general interest: a new European commitment” (2007), the need for promoting quality of social services and the relevance of organising a European strategy for such purpose are some of the main ideas.

Regulating quality

The issue of quality of services refers right away to the possibility of access to such services by all those that may require them, and so it is required that they are available, that they are accessible, in affordable economic conditions, respecting as much as possible the capacity of decision and choice of the users.

Furthermore, quality of services is a condition and decisive factor for optimising potentials of people with disabilities, for enhancing their quality of life and their social inclusion.

To manage quality and to manage with quality implies the adoption of principles, of criteria, which become reference systems for action, as if they were navigation tools for the different intervening parties, enabling service regulation, monitoring and evaluation, as for the capacity they show for solving citizens’ problems, within a framework of economic rationality.

The existence of a system that enables the accreditation of service providing entities, the certification of their respective quality, while monitoring the level of performance of organisations and ensuring the quality of the services provided, while at the same time also monitoring the level of performance of the system itself, which frames and organises service provision, regulating the respective adequacy, pertinence, its efficacy and efficiency, thus become fundamental factors and conditions for a successful Strategy and for fulfilling the mission the Strategy proposes to achieve. Two fundamental pillars of the governance model are coordination and integration of the different sectors and players, by promoting actions which are coherent, articulated and aligned with the national strategy, with the dynamics for monitoring and regulating the strategy, with the functioning of the system and with the performance of their agents.

Of the different models of quality management, more and more present and current in the competitive economy, and emerging in the public sector and in the social economy, one may consider that the use of any of them is a valuable contribution for supporting continuous improvement and learning experiences for organisations and systems. However, the specificity of social services of general interest, including those related to disabilities, and the nature of its provision, recommend the adoption of the total quality management model, of the

model of excellence, based on fundamental guiding principles, from which service providers organise and manage their intervention. In a non-prescriptive and universal way, but according to their circumstances and their context, according to their culture and models of intervention, each organisation should ensure the alignment with principles and criteria of reference, basing themselves on a quality management system, whether certified or not.

The EQUASS – European Quality in Social Services ⁽²⁰⁾

Interpreting the challenges that were starting to appear, and anticipating the need to respond to such challenges, the EPR – European Platform for Rehabilitation launched, in 2003, the basis of what would then become EQUASS – European Quality in Social Services. This system, by adopting the model of excellence of the EFQM – European Foundation for Quality Management, is based on the Principles for Quality, approved by an Awarding Committee, which integrates a large group of relevant European organisations in this sector.

(20) Further information available at www.epr.eu

These contents have been subject of update, at the translation moment.

Principles for Quality

Leadership

Organisations demonstrate leadership within the social sector internally by good governance and within the wider community by promoting positive images, challenging low expectations, best practice, more effective use of resources, innovation, and a more open and inclusive society.

Rights

Organisations are committed to protecting and promoting the rights of the person served in terms of equal opportunities, equal treatment and freedom of choice, self-determination and equal participation. Organisations are ensuring informed consent and adopting non-discrimination and positive actions within their own services. This commitment is apparent in all elements of service development and delivery and in the values of the organisation.

Ethics

Organisations operate on the basis of a Code of Ethics that respects the dignity of the person served and their families or carers that protects them from undue risk, that specifies the requirements for competence within the organisation and that promotes social justice.

Partnership

Organisations operate in partnership with public and private sector agencies, employers and worker representatives, funders and purchasers, organisations of people with disabilities, local groups and families and carers to create a continuum of services and achieve more effective service impacts and a more open society.

Participation

Organisations promote the participation and inclusion of people with disabilities at all levels of the organisation and within the community. Organisations involve users as active members of the service team. In pursuit of more equal participation and inclusion, organisations should facilitate the empowerment of the person served. They work in consultation with representative bodies and groups to support advocacy, the removal of barriers, public education and active promotion of equal opportunities.

Person centred

Organisations operate processes aiming at the improvement of quality of life of person served that are driven by the needs of both the person served and potential beneficiaries. They respect the individual's contribution by engaging them in self assessment, service-user feedback and evaluation and that value personal as well as service goals taking into account the physical and social environment of the person served. All processes are subject to regular review.

Comprehensiveness

Organisations ensure that the person served can access a continuum of holistic and community based services, which value the contribution of all users and potential partners including the local community, employers and other stakeholders and that span from early intervention to support and follow up. The services should be delivered through a multi-disciplinary team approach or multi-agency partnership with other service providers and employers.

Result orientation

Organisations are outcome focused, in terms of both perceptions and achievements, on the benefits to the person served, their family/carers, employers, other stakeholders and the community. They also aspire to the achievement of best value for their purchasers and funders. Service impacts are measured, monitored, and are an important element of continuous improvement, transparency and accountability processes.

Continuous improvement

Organisations are proactive in meeting market needs, using resources more effectively, developing and improving services and utilising research and development to achieve innovation. They are committed to staff development and learning, strive for effective communications and marketing, value user, funder and stakeholder feedback and operatzality improvement.

Adopting these principles as fundamental quality reference systems, within a perspective of total quality management, the EQUASS is a three level system:

- **Quality Assurance in Social Services (EQUASS Assurance)** – guarantees quality of service provision by certifying compliance with 38 criteria based on the Principles for Quality. It can be viewed as a fundamental requirement for operating social services, having a feasible threshold in terms of costs, efforts and feasibility.
- **Excellence in Social Services (EQUASS Excellence)** – is awarded to any service provider that can demonstrate achievements and continuous improvement on all nine Principles for Quality from three different perspectives: approach, deployment and results. The results of the certified organisations are published in order to facilitate benchmarking and bench learning.
- **Outstanding Performance in Social Services (EQUASS Award)** – is granted once a year to an EQUASS Excellence awarded organisation that takes part in a voluntary competition and proves outstanding performance on the Principles for Quality compared with the other service providers.

From the fundamental definitions to deciding on certifications, the whole system is regulated by the Awarding Committee, which integrates a group of representatives from the different European stakeholders: clients, service providers, social partners, financing entities, political decision makers.

Quality management of social disability-related services, in Portugal

As there is a European Quality Management System – the EQUASS – specifically designed for social services, and even more specifically for social disability-related services, which principles of excellence inspire the reference principles proposed by the European Commission for the disability sector, it makes all the sense that Portugal bases itself upon such system and uses it as a quality reference system for managing and monitoring the level of quality of services provided to people with disabilities, for political and technical reasons and for reasons of economic rationality.

Pillars for a quality management model, within the scope of Strategy governance:

- Allocation of public funds for service provision should only occur after the potential of compliance of the providing entities has been verified, in face of capacity requirements demanded by the quality reference system.
- The above mentioned verification of compliance materialises a process of accreditation, which should be proceeding for providers applying for the first time, and posterior for organisations already acting in the system, within a well defined time schedule, which should be as short as possible.
- The above mentioned accreditation should be regularly validated, at well defined time intervals, in a differentiated way according to the merit of performance of each organisation.
- Through accreditation of service providing entities, the quality of services is ensured, thus becoming an instrument of quality assurance for citizens, for financing and regulatory entities, and for other stakeholders as well.
- Quality audits, carried out with an educational purpose, and with the intention of supporting the development of the organisations and of the services they provide, represent a strategy for supporting posterior accreditation and decision making, within the scope of system regulation.
- Supervision of the regulation and decision making system, on the accreditation of entities, as entities with potential for providing social disability-related services is a responsibility of the National Quality Committee, chaired by the national agency responsible for coordinating policies in favour of people with disabilities, which includes representatives from the public services involved, from the representative organisations and from experts in the field of quality management of the services at stake.
- Accreditation of entities, in and of itself, does not mean that public funds are going to be awarded; such allocation is a competency of the sectorial organisms responsible for managing financial resources, which decisions are also based on other criteria, besides the requirement of accreditation, such as the need for the service and the availability of resources.

FUNDING MECHANISMS AS A STRATEGIC ELEMENT FOR CHANGE

The way Portugal has ensured support and service provision in the domain of people with disabilities, as a social responsibility, assuming that the impacts of disability are an expense to be born by society, within the scope of social solidarity, resulted from a political choice that can be characterised, in brief, by a small intervention from the service providing entities of public nature – at the level of specialised services complementary to general services and resources – with the option of granting support to the private sector, namely to the associative and to the cooperative sectors.

The organisation and development model of that partnership, somehow, led to a “state hidden model”, creating strong ties between the private institutions and the State, a kind of semi-organic dependence, resulting from the funding framework mechanisms and from the adjacent regulation of the institutional culture of some sectors of the Administration, in a clear relationship of tutelage, at times clearly assumed. The relationships of partnership which were established could at times be considered more as authoritarian relationships than really as paritarian ones, with a regulatory framework not completely formalised and stable, in some of the policy domains.

Allocation and management of public resources has been very much centred on criteria and concerns of administrative and financial nature, with little focus on issues of assessment of results and of their relevance for citizens and for society, to a certain extent, the general management dynamics in the country and dominant even in the EU funding, which became the main funding mechanism for some of the services at stake.

Due to the own historical dynamics, that developed since 1974, Portugal felt the need to mobilise dynamics centred in searching for the greatest possible generalisation of access to support and services, by adopting a model of intensive investment, centred on the creation of responses and support structures, aiming at overcoming the existing scarcity at the time. Presently, Portugal has a network of services with virtues and limitations, more similar to a semi-public dynamics than really to a service “market”. To bet on private provision should continue, but at the same time it should be optimised through a greater articulation and cooperation between the public sector, the solidary sector and the private sector/market.

Within the context of formulating and organising a new strategy, the issue of the model and framework principles for granting public funds takes up a critical role, as the main pillar of the governance model, as it can become the fundamental lever for fulfilling the fundamental options of the strategy, working as the inducing element of the foreseen developments.

Dynamics of a new financing model

Even though it is necessary to find a formula of balanced combination between the emerging trends at European and national levels (namely the new approaches in terms of management, and the dynamics of competition and of the internal market, to be progressively applied as well to social services) and the specific nature of social services, the new trends must be considered at the level of conceptualising and organising the strategy for providing social disability-related services.

The relationship between funding and results achieved, the decreased influence and responsibility of the State, the increased responsibility of the citizens, families, communities, social players, **the new financing model**, realistic in the present but also oriented towards the future, should be structured from a set of **fundamental guidelines**, also aligned with the conceptual pillars of the new strategy of action.

- Financial resources managed with the concern of ensuring universal access to services, of guaranteeing quality services and sustainability of responses to the citizens.
- Convergence and conciliation of sectorial responsibilities by funding the service provided, with the need of ensuring integrated and individualised response continuums, delocalising the centre of gravity of the issue from the Administration criteria, to the integrated nature of problems and the individualised needs of citizens, translated as individual plans, from the assessment of needs of each one.
- Evolution of the management model, centred on managing activities, on eminently administrative management, also and fundamentally, to management of results and impacts, either upon the citizens' quality of life, or upon the social impacts of interventions.
- Evolution of the model for funding organisations, through subsidies or other ways of granting funds, in a global and aggregated way, to financing services, through programme contracts, of pluri-annual nature, contracting and parametering with rigour the different responsibilities of the different parties, in order to enable assessing the quality of services and indexing the resources to allocate. Progressive evolution of the funding mechanisms towards the formula of personal budgets, aggregated to individual plans, as their financial support, with a tendency for being managed with the active involvement of the citizens and their families, or directly by themselves, mobilising and ensuring a greater participation and co-accountability of the citizens, of their families, as

well as a progressive freedom of decision and choice, coherently with the principles of the social model of disability, also allowing the State to have an accurate understanding of the resources that need to be allocated and a greater correlation between needs, results and type and amount of resources involved.

- To develop public-private partnerships and progressive mobilisation of complementary resources to those ensured by public funds.
- To leverage decisions at the level of the financing systems, in the reference systems and quality criteria, in the quality management system, which are the bases for all monitoring and assessment activities and for decision making.
- To promote excellence, best practices, recognising service providers in a differentiated way, according to their merit in resource management, to the quality of services they provide, to the responses they ensure to citizens, according to an approach of positive differentiation.

As people are the centre of all policies and services that make them operational, it makes all the sense to move towards a management and financing model centred on citizens' problems and needs, considered on an individual basis, in the resolution of their problems, in greater participation and involvement in decision making, also making them accountable for the best use of the opportunities made available to them.

THE SERVICES NETWORK

One of the first and most fundamental circumstances for a successful Strategy for Enhancing the Quality of Life, has to do with creating the necessary and appropriate conditions for ensuring that the social responses that promote it, the support social services, are closely available, are accessible, are sustainable, and can be mobilised by all those that need them, regardless of their economic condition.

The present model for organising service provision is structured on the basis of different networks of services, organised according to the own dynamics of each policy sector, in a logic of addition, with poor levels of articulation and interaction between them, even if often coexisting, living together in the same institutional contexts of some service providers.

The option for an integrated and transversal political strategy and for an

integrated governance model imply that a new approach be adopted at the level of how responses, how the services that make the transversal policies and the sectorial policies that fulfil them operational, are organised and function. Thus, the challenge ahead of us is how to move from a logics of *services networks* to that of a *services network*, including, in an integrated way, the general structures and the specialised resource centres, acting in articulation and complementarily between them, in a logics of trans-sectorial cooperation, ensuring integrated and coherent response continuums for citizens, focussing on their needs and expectations, oriented towards and by the client, rationalising and optimising all the resources involved.

The fundamental challenge for Portugal, at this level, is to move from a dynamics of densification of services networks, typical of a period centred on openness to solutions that added up over time, in a context of absence or lack of responses, to the rationalisation of a services network. At the same time, it is important to evolve from the present semi-public model of service provision, where private provision – complementary to public provision – is still very much oriented by and under the tutelage of the financing organisms, placing the service providing organisations under some dependence of the State, while they also transfer to the State some responsibilities of organisational nature, towards a truly private and independent model, in which all roles are clearly defined, instituted and regulated, with mutual commitment, but with statutory and functional independence, favouring the emergence of competitive dynamics, that generate continuous competitiveness and development in the quality of responses.

To define a **network of services** for the needs of people with disabilities, just as for any other social needs, should be framed by some general **guiding principles**, as the fundamental criteria for decision making at this level, within a logics of searching for maximisation of intended results and of the levels of citizen satisfaction.

- **National policy(ies), regional/local intervention** – within the framework of defining national and sectorial policies, national reference systems for organising and operationalising services, monitoring systems and evaluation thereof – of the responsibility of national instances – the responsibility for organising, monitoring and managing service provision for citizens, under the responsibility of public entities, of public-private partnerships or of private entities, should be assigned to regional/local instances, thus ensuring proximity, active participation of citizens and communities in the identification of problems and

needs, in formulating the respective solutions, within a framework of mutual commitment and responsibility. Such decentralisation should safeguard any risks of inequalities being generated at territorial level (in no way new or specific ones of such option, as they already exist at present) and of the transfer of competencies not being followed by the transfer of financial resources and actual responsibility. Greater impact of the policy (ies) at local level shall be ensured by such functional decentralisation to the territories.

- **Anchorage of needs** – network dimensioning, response location and configuration, should be what results from the context needs, from the territory needs, thought out and organised according to criteria of reference, transparent and universally applicable.
- **Conceptual updating** – citizen and territory needs shall be conceived in the light of the updated and appropriate conceptual and policy models of reference.
- **Holistic and integrated nature** – as the problems to be solved have a comprehensive and complex nature, and citizens are multidimensional subjects, integrated wholes, responses should also have a holistic and comprehensive nature, responding to the multiple and diverse needs of citizens, conceived and made available in an integrated way, organised and structured according to the nature of the problem and not according to other criteria, either of administrative nature or of any other nature.
- **Economic rationality** – universal coverage, rationalisation and optimisation of results and resources, are critical challenges, ensuring effective responses, with no duplications, redundancies or overlapping.
- **Demand pulled** – from a supply based model of service provision, structured from logics and dynamics organised by service providers, one must move to a demand based model, organising service provision from the assessment of needs and from specific potentials of each citizen, guided by individual plans, within a framework of individualisation and flexibility.
- **Sustainable development** – structuring and development of the network, unequivocally guided by the above mentioned principles, should ensure continuous responses, with steady but sustainable progress, integrating less definite, less formal and less formalised practices, while those of higher value are not available, without however affecting the necessary developments.

Framed and guided by the above mentioned principles, as well as by the fundamental goals of the political strategy – to promote quality of life, social inclusion, giving priority to activation, followed by compensation and support measures – the **services network** shall integrate several **dimensions**.

- General community structures, as the primary and natural context for inclusion.
- Specialised structures, intervening in an articulated way and complementarily with general structures, for promoting inclusion, in activation strategies:
 - > **inclusion support centres** – responsible for assessing disabilities, needs and potentials, for preparing individual plans and for supporting citizens and families in mobilising and accessing resources and for managing individual plans, in a dynamics of an integrated and trans-sectorial centre, acting according to a logics of case management;
 - > **inclusion resource centres** – responsible for specialised services and support, complementary to those already made available by general structures;
 - > **rehabilitation centres** – intervening in thematic domains of rehabilitation, and should be progressively guided towards the integrated and integral model of rehabilitation, in what concerns people with disabilities acquired as a consequence of disease or accidents.
- Specific social responses of support to dynamics of social inclusion for citizens in a condition of limitations to inclusion due to general social dynamics, in articulation and complementarily to social responses from the community which may be mobilised for such purpose.

The necessary progress of the present structure of responses for the proposed scenarios shall also induce a dynamics of improved quality of services, as the choices shall be based on quality criteria and shall stimulate service providing organisations to promote continuous improvement of their services.

At this level, a deep reform of the present structure of service network is required, based on units, which dimension places difficulties in order to face the new challenges ahead of us (similarly to many other sectors in the country), and is thus a fundamental challenge to the modernisation of organisations, the development of their competencies and promotion of their empowerment. To gain scale, dimension, in order to increase management capacity and to ensure greater efficacy and efficiency, necessarily has to be compatible with another fundamental principle, that of ensuring availability of services to all that may need them, in

a logics of proximity. Even though the need to re-think the issue of structure as a fundamental element for empowerment is an obvious one, the pillar of proximity in service provision can not be lost, what does not necessarily mean such an intimate and irrational proximity in its configuration and costs. In the same way, the way general resources (schools, training centres, etc.) and specialised resources, which shall take up a complementary role to the former ones and not structured as parallel networks, are going to be articulated and interact, within a framework of optimisation of resources and responses, has to be re-thought.

Of course one must assume that there are difficulties in implementing these new dynamics, ahead of which normally are the competencies for participation and decision making that such models require from the citizens, as well as the present management practices, of the system and of the organisations. If, as far as the latter, what is required is hard work of development, regarding the former, it implies the adoption of a global strategy of intervention promoting empowerment and supporting the citizens and their families to know and to exercise their rights, and to access them and demand their fulfilment, which challenges require counselling and orientation services and a strategy clearly in line with this philosophy, by the representative organisations and by service providing organisations.

As the major goal of policies and services for people with disabilities is the promotion of autonomy and management capacity, and self determination of their own lives, while the right to their own decision making is acknowledged and their active participation required, a model such as the one just proposed, in close harmony with the above mentioned principles, is absolutely necessary and requires an urgent and enlightened action in order to create the conditions required for its implementation.

Obviously, it is a path to follow with realism and care, without putting at risk the desired balances in order to achieve a safe and sustained progress, however it has to be walked with determination and confidence, which follow from the virtues in contains and from the benefits it ensures to all stakeholders.



Chapter 10.
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Chapter 11.
Annexes

ANNEX A

Products of the Study

“Modelling Policies and Practices of Social Inclusion for People with disabilities in Portugal” *

- Recomendações para a programação do QREN – Quadro de Referência Estratégico Nacional 2007/2013
Recommendations for the programming of the SNRF – Strategic National Reference Framework 2007/2013
- Mais qualidade de vida para as pessoas com deficiências e incapacidades – Uma estratégia para Portugal **
Enhancing the quality of life of people with disabilities – A Strategy for Portugal
- Elementos de caracterização das pessoas com deficiências e incapacidades em Portugal **
Characterising elements of people with disabilities in Portugal
- O sistema de reabilitação e as trajetórias de vida das pessoas com deficiências e incapacidades em Portugal **
The rehabilitation system and the life pathways of people with disabilities in Portugal

Complementary documents *

- Modelização – desafios, riscos e princípios orientadores
Modelling – challenges, risks and guiding principles
- Delimitação e operacionalização do conceito de deficiência
Delimitating the concept of disability and making it operational
- Análise comparada de modelos de políticas a favor das pessoas com deficiências e incapacidades
Comparative analysis of policy models for people with disabilities
- Programas e medidas relativos à deficiência
Programmes and measures related to disability
- Qualidade de vida – modelo conceptual
Quality of Life – conceptual model
- Metodologia de avaliação de impactos
Impact evaluation methodology

- Gestão de casos
Case management
- An international perspective on modelling disability
- The contribution of International Classification of Functioning, Disability and Health for Children and Youth to Special Needs Education
- The International Classification of Functioning, Disability and Health as a framework for disability policy design and deployment

Pathway documents *

- Report and resources from the workshop “Modelling disability within a social policy framework”
- Report and resources from the workshop “Design of disability policies and measures in Portugal”
- Report and resources from the workshop “Design of a governance model for the implementation of a National Disability Strategy in Portugal”

* Available for download at www.crbg.pt ** Hard copy also available

ANNEX B

Modelling: a shared pathway

The Study “Modelling Social Inclusion Policies and Practices for People with Disabilities in Portugal” counted on the involvement of different government departments, of entities representing people with disabilities and of different experts.

Articulation

Secretaria de Estado Adjunta e da Reabilitação
Secretary of State Adjunct and for Rehabilitation

Follow-up Committee

• Ministério do Trabalho e da Solidariedade Social <i>Ministry of Labour and Social Solidarity</i>	
> SEAR – Secretaria de Estado Adjunta e da Reabilitação <i>Secretary of State Adjunct and for Rehabilitation</i>	Ana Salvado
> INR – Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>	Rui Carreteiro
> IEFP – Instituto do Emprego e Formação Profissional <i>Employment and Vocational Training Institute</i>	Leonardo Conceição
> ISS – Instituto da Segurança Social <i>Social Security Institute</i>	Alexandra Amorim
> GEP – Gabinete de Estratégia e Planeamento <i>Office for Strategy and Planning</i>	João Nogueira Rui Nicola
• Ministério da Saúde <i>Ministry of Health</i>	Maria Beatriz Couto
• Ministério da Educação <i>Ministry of Education</i>	M. Joaquim Lopes Ramos
• Ministério das Obras Públicas, Transportes e Comunicações <i>Ministry of Public Works, Transport and Communications</i>	João Valente Pires

Collaborations

Alda Gonçalves	Instituto da Segurança Social <i>Social Security Institute</i>
Alexandra Pimenta	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
António Lopes	Direcção Regional de Educação do Centro <i>Regional Directorate of Education of the Centre</i>
Beatriz Jacinto	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
Carla Pereira	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
Carmen Duarte	CECD Mira-Sintra <i>Portuguese disability-related social services provider</i>
Carmo Medeiros	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
Celina Sol	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
Domingos Rosa	Fundação AFID Diferença <i>Portuguese disability-related social services provider</i>
Filomena Pereira	Direcção-Geral de Inovação e Desenvolvimento Curricular <i>General Directorate for Innovation and Curriculum Development</i>
Isabel Felgueiras	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
Isabel Pinheiro	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
José Carvalhinho	Câmara Municipal da Lousã – Provedor Municipal das Pessoas com Incapacidade <i>Municipality of Lousã – Municipal Ombudsman for Persons with Disabilities</i>
Luís Pardal	FENACERCI – Federação Nacional de Cooperativas de Solidariedade Social <i>National Federation of Social Solidarity Cooperatives</i>

Miguel Ferro	Instituto Nacional para a Reabilitação <i>National Rehabilitation Institute</i>
Norberta Falcão	Agência Nacional para a Qualificação <i>National Qualification Authority</i>
Rui Godinho	IESE – Instituto de Estudos Sociais e Económicos <i>Institute for Social and Economic Studies</i>
Sandra Marques	FENACERCI – Federação Nacional de Cooperativas de Solidariedade Social <i>National Federation of Social Solidarity Cooperatives</i>

Involvement

Conselho Nacional para a Reabilitação e Integração das Pessoas com Deficiência
National Council for the Rehabilitation and Integration of the Handicapped

With the support of

EPR – European Platform for Rehabilitation

- 1.** Contributos para um Modelo de Análise dos Impactos das Intervenções do Fundo Social Europeu no Domínio das Pessoas com Deficiência em Portugal
Contributions for a Model for Analysing the Impacts of Interventions of the European Social Fund upon the Domain of People with Disabilities in Portugal
- 2.** Os Impactos do Fundo Social Europeu na Reabilitação Profissional de Pessoas com Deficiência em Portugal
The Impacts of the European Social Fund upon Vocational Rehabilitation of People with Disabilities in Portugal
- 3.** Desafios do Movimento da Qualidade ao Sistema e às Organizações que Promovem a Empregabilidade e o Emprego das Pessoas com Deficiência
Quality Movement Challenges to the System and Organisations that Promote Employability and Employment of People with Disabilities
- 4.** Organização da Formação e Certificação de Competências: Desafios e Contributos para o Modelo de Intervenção
Organisation of Training and Certification of Competencies: Challenges and Contributions for an Intervention Model
- 5.** Acidentes de Trabalho e Doenças Profissionais em Portugal: Das Práticas Actuais aos Novos Desafios
Work-related Accidents and Occupational Diseases in Portugal: From the Current Practices to the New Challenges
- 6.** Acidentes de Trabalho e Doenças Profissionais em Portugal: Impactos nos Trabalhadores e Famílias
Work-related Accidents and Occupational Diseases in Portugal: Impacts upon Workers and Their Families
- 7.** Acidentes de Trabalho e Doenças Profissionais em Portugal: Riscos Profissionais: Factores e Desafios
Work-related Accidents and Occupational Diseases in Portugal: Occupational Risks: Factors and Challenges

- 8.** Acidentes de Trabalho e Doenças Profissionais em Portugal:
Regime Jurídico da Reparação dos Danos
Work-related Accidents and Occupational Diseases in Portugal: Legal Regimen for Damage Repair

- 9.** Acidentes de Trabalho e Doenças Profissionais em Portugal:
Disability Management: Uma Nova Perspectiva de Gerir a Doença, a Incapacidade e a Deficiência nas Empresas
Work-related Accidents and Occupational Diseases in Portugal: Disability Management: A New Approach for Managing Disease and Disabilities in Companies

- 10.** Mais Qualidade de Vida para as Pessoas com Deficiências e Incapacidades: Uma Estratégia para Portugal
Enhancing the Quality of Life of People with Disabilities: A Strategy for Portugal

- 11.** Elementos de Caracterização das Pessoas com Deficiências e Incapacidades em Portugal
Characterising Elements of People with Disabilities in Portugal

- 12.** O Sistema de Reabilitação e as Trajectórias de Vida das Pessoas com Deficiências e Incapacidades em Portugal
The Rehabilitation System and the Life Pathways of People with Disabilities in Portugal

- 13.** Enhancing the Quality of Life of People with Disabilities: A Strategy for Portugal (English version – Study 10)