ALTER, European Journal of Disability Research 5 (2011) 177–191

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Research paper

Rethinking policies for persons with disabilities through the capability approach: The case of the Tuscany Region

Re-penser les politiques du handicap au travers de l'approche par les capabilités : le cas de la région toscane

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A R T I C L E I N F O

Article history:
Received 17 July 2010
Accepted 13 December 2010
Available online5 July 2011

Keywords:
Disability studies
Operationalisation of the capability approach
Life project
Mosaic strategy

A B S T R A C T

The aim of this article is to describe how the capability approach can be applied in Italy, within a regional context, to enhance social policies designed for persons with disabilities. The case of the Tuscany Region is taken as an example. The article presents several tools meant to reach this goal. Although these are thought to answer different identifiable problems, they should be implemented together in order to reshape effectively the whole regional system. The most relevant instrument, according to the 'dis-capability' framework, is the life project within a person-centred planning strategy. This gives the possibility of carrying out an accurate mapping of the person's needs, characteristics, and desires throughout a personal reflection process. If the life project represents the pivot around which we define a 'mosaic strategy' – i.e. a step-by-step process of actions for the person with disabilities – an effective reform of social policies for people with disabilities needs to be complemented with other relevant instruments and changes in order to favour personal and collective flourishing. These changes include – besides a cultural shift by political leaders – a structural reorganisation of the health and social services delivery, an up-grading of the competencies and, above all, a well-organized and capillary informative system.

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doi:10.1016/j.alter.2011.05.002

RÉSUMÉ

Mots clés :
Études sur le handicap
Opérationnalisation de l'approche par les capabilités
Projet de vie
Stratégie mosaïque

L'objectif de cet article est de décrire comment l'approche par les capabilités peut être mise en œuvre pour repenser et promouvoir les politiques sociales d'une région en Italie à l'endroit des personnes handicapées. Cet article présente plusieurs outils conçus dans ce but ; le cas de la Toscane est pris comme exemple. Bien que ces outils aient été élaborés pour répondre à des problèmes spécifiques, ils sont à mettre en œuvre conjointement afin de remodeler le système régional dans son ensemble. L'instrument central, dans le schéma de la « discapabilité », est le projet de vie placé au cœur d'une stratégie de planification centrée autour de l'individu. Cette approche donne la possibilité d'élaborer une cartographie précise des besoins de la personne, de ses caractéristiques et de ses souhaits au travers d'un processus personnalisé d'élaboration. Si le projet de vie représente le pivot autour duquel nous définissons ce que nous appelons une stratégie en mosaïque — c'est-à-dire un processus de mise en œuvre progressive de diverses actions au profit de la personne handicapée — une réforme effective des politiques sociales nécessite, pour être complétée, d'autres changements et outils aptes à favoriser l'épanouissement de l'individu et de la collectivité autour de lui. Au-delà d'un changement de culture des décideurs politiques, ces changements consistent en une réorganisation structurelle des prestations des services sociaux et de santé, en une mise à jour des compétences et, par-dessus tout, une coordination des intervenants bien organisée et en la mise en place d'un système d'information par capillarité correctement structuré.

Background

As argued in the first article of this special issue, the capability approach (CA) considers development as a process of expansion of people's opportunities and freedoms, acknowledges the importance of maintaining dignity and the right to express their needs and aspirations (Trani et al., this issue).

Since the CA lays emphasis on the capacity of individuals to be active agents of change, it can gain substance and further significance from people's active participation (Sen, 2009a, 2009b)[1]. Therefore, if capabilities are people's real freedoms to enjoy the beings and doings they value and have reason to value (Sen, 1980; Sen, 1999), the other type of freedom that development should expand is process or agency freedom. This refers to the person's ability to act and bring about change and to pursue the goals that she/he values (Sen, 1999). It is the freedom to achieve whatever the person, as a responsible agent, decides he or she should achieve (Sen, 1985, p. 204) and is central "in assessing what a person can do in line with his or her conception of the good" (Sen, 1985, p. 206). Since other people often manoeuvre the levers that expand choices (Sen, 1992), it is relevant to point out that agency does not necessarily imply 'control'. However, agency remains central as well as the level of participation. This means considering each individual not simply as recipient of freedoms, but as an active social actor and agent in their communities with her/his own priorities, strategies and aspirations. This represents a crucial factor for public policies since it encourages individuals' participation in economic, social, and political action and enables them to take decisions as active agents of change, rather than as passive recipients of medical care (Ruger, 2007). In this perspective, the policy maker's task is that of

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[1] When mentally disabled people are considered, caregivers can also be actively involved (see the concept of E-capability in Bellanca et al., this issue).

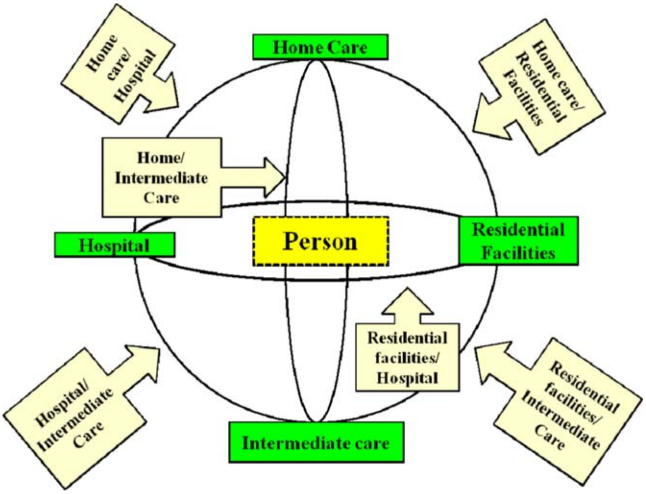

Fig. 1. Normative map of integrate pathways of care.
Authors' elaboration from Fondazione Zancan (2008) (p. 23).

setting the conditions that facilitate people's abilities to lead flourishing lives (Deneulin and Stewart, 2002), and to provide the multiple possibilities through which an individual can achieve fulfillment (Nussbaum, 2000).

The aim of this article is to describe how the capability approach can be applied within a regional system in Italy in order to reshape and to enhance social policies designed for persons with disabilities. Taking into consideration this goal, we present some relevant instruments to be implemented together.

Tuscany Region is at the forefront among the Italian regions that are promoting policies for the integration of social and health care pathways for people with disabilities (Bissolo & Fazzi, 2007; D'Adamo & Giordano, 2008). Fig. 1 shows in normative terms how the Italian regional system should work in theory. However, the actual implementation faces also in Tuscany two main difficulties (Bonfanti & Bellanca, 2011). The first problem is that the universal service delivery is very much supply and health oriented, with very limited exceptions such as the "independent life" project (Biggeri *et al.*, 2011). In other words, persons with disabilities (and their caregivers) do not participate to the decision-making process regarding his/her needs and aspirations. This lack of participation implies a mismatch between people's needs/aspirations and the measures designed by policy makers and implemented by local authorities; an excessive focus on the impairment and thus, a conceptualisation of the well-being and well-becoming of the persons with disabilities focused mainly on the dimension of health. The second problem regards the difficulties encountered in coordinating the system of public health and social services (organisation and delivery), on the one side, and the difficulty in coordinating the large quantity of activities carried out by voluntary associations and by non-governmental organisation, on the other. Although the territory presents a very rich and complex social and institutional structure – in which both existing associations and the Tuscany Region authorities have been working in partnership for years to improve policies and services for persons with disabilities (Gori, 2008), limited efficacy is recorded due to the poor coordination as well as to the very poor systemic use and control of the information on activities and resources offered.

According to the framework of 'dis-capability' (Bellanca et al., this issue) we define as disabled someone who has a limited capability set compared to his/her objectives, ambitions and system of values. This self-representation is derived from a process of social acknowledgement, which also includes medical assessments. However, as a result of this process, it is possible to understand a disability only through individual evaluations and therefore, political interventions aimed at improving such situations need to be tailored to a person's requirements.

In order to give substance to this statement, a person-centred strategy is our starting point[2]. We identify the 'life project'[3] as the most relevant instrument since it is the mainstay of the 'dis-capability' framework operationalisation as it requires the person to undertake a process of individual and social empowerment. The life project is a powerful tool which can/must be used to suggest/decide which goals and strategies a person with disability would follow and which actions and services (either existent or non-existent and either public or private) are needed (Barbuto et al., this issue). It requires willingness and often an individual or group process (*parcours de vie*), e.g. through peer-counseling, potentially preceded by the participation to a self-help group (Barbuto et al., this issue). The life project encourages the person with disability to define and justify his/her life objectives through a tailored project/planning. The personal process gives the possibility of carrying out an accurate mapping of the person's needs, characteristics and desires and aims at clarifying one's main goals at identifying the elements which will enable the achievement of these objectives (for more details: Horna Padrón, 2005; Barbuto et al., this issue).

From a capability approach perspective this is the potential starting point to transform the person with disabilities into an active agent of change and to give the possibility to develop a system of services which take into account the values and aspirations of the main stakeholders. In this direction, the overall reform must necessarily provide support also to the caregivers, i.e. usually the family of the person with disabilities. Indeed, through their own capabilities set, caregivers fulfill disabled people's psychophysical needs on a daily basis, thus influencing not only their well-being, but also encouraging a positive self-perception.

However, in order to apply the overall reform, social policies inspired by the CA must consist of some essential changes in the coordination of the system as well as in processes of service provision. Furthermore, other instruments such as peer-counseling and self-help groups could be developed to improve individual and community deliberative processes (Barbuto et al., this issue for details).

The next section presents the 'mosaic strategy' which, by promoting a participatory approach to the identification of the means necessary to fulfill disabled people's actual desires and needs, makes the provision of public and private services more efficient and effective. The third section illustrates the other instruments and reforms planned to introduce such a strategy within the Tuscan system. In the last section we present and discuss the main conclusions.

The mosaic strategy as an operative tool

In this section we present an innovative tool, i.e. the mosaic strategy, which should facilitate: (a) the drafting of the person with disability's life project; (b) the matching between the person's needs/desire (demand) and the provision of public and private services (supply); (c) a personal reflection over constraints and trades-off between the actual desires and needs of the person with disabilities and the limited amount of resources available.

The mosaic strategy consists mainly of three steps. The first step aims at unpacking the needs and desires of the person with disabilities. In order to get this goal, the person is encouraged to autonomously draft a life project (when this is not possible, she/he can be supported by a peer counselor, her/his main caregiver and/or her/his case manager and/or the social worker), (Barbuto et al., this issue).

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[2] The Person-Centred Planning, for instance, is a process that facilitates the inclusion of persons with disabilities into their communities, including neighbourhood, school, and work (O'Brien et al., 1997; Robertson et al., 2007). According to Kincaid (1996) (p. 440), the general goals of Person-Centred Planning for the individual include: being present and participating in community life, gaining and maintaining satisfying relationships, expressing preferences and making choices in everyday life, having opportunities to fulfil respected roles and to live with dignity, continuing to develop personal competencies. In other words, as the capability approach, it denotes a shift in focus from finding out what is wrong with a person and how to repair it, to identifying capacities, and how to enhance them so that a person can live the life they or caregivers envisage (O'Brien et al., 1997).

[3] According to Parsons et al. (2009) (p. 49) those people who were supported in an individualised way (individual needs planning) were provided with more flexible, creative planning processes, which led to more opportunities that were coherent with the person's culture, needs, and preferences.

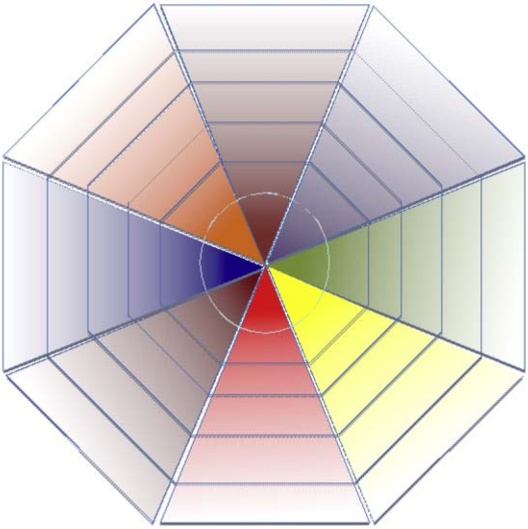

Fig. 2. The mosaic and the well-being dimensions in the capability space.
Authors' elaboration.

In the second step the mosaic project is validated. This may imply a re-drafting of the life project jointly by the person with disability and her/his case manager and subsequently, being discussed with a multidisciplinary team (see next section for details). Therefore, this self-representation is derived from a process of social acknowledgement, which also includes medical and social assessments of actual achievements.

In the third step, the focus is on the implementation of the mosaic, namely on the identification of the barriers and resources connected with the provision of the services, necessary to satisfy the person's needs and desires.

The full potential life project can be represented as a mosaic made up of concentric octagons (Fig. 2). The surface of each small octagon is divided into eight wedges, each one corresponding to one of the domains or dimensions of well-being. The eight dimensions are, as explained in detail later, a combination of Nussbaum (2000) ten central capabilities, our research effort (Biggeri et al., 2006). Obviously, further sub-dimensions could be examined.

Each sector of the mosaic consists of *tesserae*[4] of a given colour whose intensity decreases from the centre to the perimeter of the mosaic. The stronger the importance attributed to a certain dimension of well-being or well-becoming, the darker the colour. The colours of the mosaic represent the dimensions deemed important for a person's well-being and well-becoming. The centre of the mosaic is characterised by a nucleus where colours are darker and common to all individuals. Moving towards the edges of the mosaic, each person decides which colours he/she wants to make more salient, according to his/her preferences or values. In other words, while some dimensions of well-being are essential for the flourishing of any human being (as defined in the United Nation Convention for the Rights of Persons with Disabilities), others play a nuanced role depending on the person's characteristics and values.

Therefore, the starting point in the elaboration of the life project consists in identifying the main domains/dimensions of well-being/well-becoming. Thanks to the research carried out for the Tuscany Region and to earlier works, we have identified the following aspects as essential in order to achieve a good human life: psychophysical well-being, affection and care, self care, freedom of choice, bodily integrity, communication, social and political participation, education and knowledge, work, mobility,

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[4] A tessera (plural: *tesserae*) is an individual tile in a mosaic, usually formed in the shape of a cube.

sport and recreational activities, residence/house, respect, spiritual/religion dimension (Biggeri et al., 2006; Biggeri and Libanora, 2011). For the sake of simplicity and following Nussbaum (2000, 2002a, 2002b, 2003, 2006)[5] and other authors' works[6], we can reduce these dimensions to eight essential domains[7]:

- life and physical health;
- emotions: love and care;
- social relations and participation;
- control over one's environment: agency, autonomy and respect, shelter and environment;
- education and knowledge;
- practical reasons 1: paid work and other projects;
- practical reasons 2: mobility;
- personal expression and recreational activities: "sense, imagination and thought", spiritual/religion, sport and recreational activities.

Please note that in Table 1 these eight domains are linked to the various sections of the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

The first and crucial step towards establishing the life project consists of identifying the person's priorities. Each of them is associated to a new *tessera* included in the corresponding sector representing one of the eight dimensions that encompass the multiple needs, activities and desires which characterise any human being (Fig. 3a). This process must also take into account the actual level of the person's functionings as well as the available resources/opportunities.

The life project/mosaic is a personal, participatory, necessarily holistic, never definitive, multicoloured, multidimensional and dynamic elaboration. The choice of placing a certain need, e.g. the desire to practice a sport, in the 'sector mobility' instead of in the 'sector social relations' is absolutely subjective and, therefore, neither can it nor must it be established *ex-ante* by professionals or local authorities (Fig. 3b). It is relevant to underline that this person-centred planning is highly time-consuming since it requires the active participation of the person to the definition of her/his future plans (in this sense adaptive preference are at least taken into account) (Barbuto et al., this issue).

The construction of the mosaic represents the premise to identify a range of interventions that can satisfy the needs and aspirations defined in the mosaic. Carrying out such an exercise calls for every person with a disability to reflect on the specific objectives that s/he wants to/can achieve within the selected dimensions (Pompei et al., 2004, 2005). For an explanation on how the deliberative process is expected to take place and its modalities please see Barbuto et al. (this issue). As the process develops, individual and collective barriers and resources (i.e. the conversion factors) are identified. According to the CA living a decent life for a person with disabilities does not mean conforming to normality; it involves an expansion of the opportunities open to a person (Bellanca et al., this issue). The capability approach promotes a conception of public action which is not restricted to passively distribute rights or resources, but acts on individual, social and environmental factors that affect the opportunities of individuals to convert them into a set of capabilities and functionings.

In addition, in accordance with the theoretical capability framework, one would expect that attention is paid not only to the means (resources) made available by public policies but also to how public action provides conditions and entitlements to increase and expand people's capabilities and choices.

The next step consists in understanding which services are actually available to respond to the needs and desires expressed by the life project (matching process), considering that different persons

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[5] Nussbaum (2003) (p. 41–42) presented the following list of central human capabilities: 1. Life; 2. Body Health; 3. Body Integrity; 4. Sense, Imagination and Thought; 5. Emotions; 6. Practical Reasons; 7. Affiliation; 8. Other species; 9. Play; 10. Control Over One's Environment.

[6] Robeyns (2003) presents the following list for exploring gender inequalities among adults: 1. Life and physical health; 2. Mental well-being; 3. Bodily Integrity and Safety; 4. Social relations; 5. Political empowerment; 6. Education and knowledge; 7. Domestic work and nonmarket care; 8. Paid work and other projects; 9. Shelter and environment; 10. Mobility: being able to be mobile; 11. Leisure activities; 12. Time-autonomy; 13. Respect; and 14. Religion (including the capability not to be religious). Works on personal identity (e.g. Ville et al., 2005) were also taken into consideration.

[7] Here the words domain and dimension are used interchangeably.

Table 1
The eight dimensions of the life project and their relation with the ICF chapters.

Capability DOMAINS	Life project dimensions and ICF	Relation to ICF			
		Body functions	Body structures	Activity and participation	Environmental factors
Life and physical health	Health	All chapters	All chapters		Ch. 5 (e580)
Emotions: love and care	Affective and care relations			Ch. 7 (d760–770)	Ch. 1 (e125); 3; 4; 5 (e555)
Social relations and participation	Social relations (including communication)			Ch. 3; 7 (d710–750); 9	
Control over one's environment: agency and autonomy and respect shelter, and environment	Autonomy, i.e. aspects related to agency and empowerment (self care, freedom of choice, residency, respect, money management)			Ch. 2; 5; 6; 8 (d860–899)	Ch. 5 (e575)
Education and knowledge	Training (education and knowledge)			Ch. 1; 8 (d810–839)	Ch. 1 (e130); 5 (e585)
Practical reasons 1: paid work and other projects	Job and Income (for adults)			Ch. 8 (d840–859)	Ch. 1 (e135); 5 (e590)
Practical reasons 2: mobility	Mobility			Ch. 4	Ch. 1 (e120); 5 (e540)
Personal expression and recreational activities: sense, imagination and thought, spiritual/religion, sport and recreational activities	Personal expression (sport and recreational activities, religion, social and political participation)				Ch. 1 (e140); 5 (e520)

with disability may consider a given service to be more or less important. Indeed, the services provided within a given territory (public and/or private, depending on availability) correspond (or should correspond) to the mosaic/life project. Therefore, it is imperative that during the decision-making process, social service professional is able to contrast the needs expressed by the person with disability and the mapping of the tools and services which can be activated or newly introduced to match the needs and desires. Existing resources are devoted to needs according to priorities established through dialogue between professionals and beneficiaries (Barbuto et al., this issue). The allocation of resources constitutes a political decision. Indeed, after public discussion and comparison of needs and resources, it is necessary that policy makers assume responsibility about how to allocate scarce means according to a value judgment. This avoids two types of pitfalls linked to trade-offs that are often made and that are clear in the following examples: (i) the case of a person with reduced mobility who is an avid cinema-goer, and who is allowed to channel all available resources at his/her disposal towards the purchase of DVDs and cinema tickets, making the acquirement of a needed prosthesis impossible; (ii) the case of a person with the same impairment, having no resources to cultivate his/her marked interest for painting because all available funding has been used for the purchase of a prosthesis and the payment of rehabilitation therapies.

Fig. 4 represents the other side of the coin, i.e. an outline of the ranking of the tools through which, according to the local government, needs of persons with disability can be progressively met.

The different concentric circles represent the degree of priority attributed to the given tools and the corresponding financial commitment of local government to secure these: full, partial or none. While some services are clearly connected to a basic capability (corresponding to a fundamental right), others, while being useful, can only be suggested. However, local administrative authorities may play an active and very relevant role for the well-being/well-becoming of persons with disabilities by identifying professionals, cooperatives and associations providing the specific service within a given

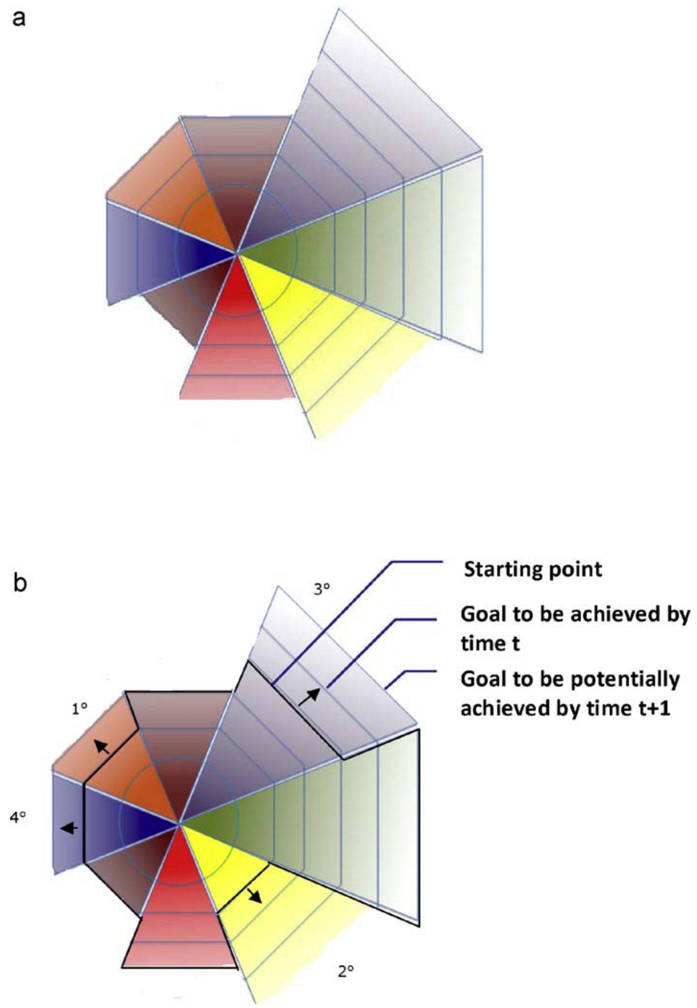

Fig. 3. a: the mosaic of the personal well-being dimensions and the life project; b: life project, well-being dimensions and the mosaic strategy.
Authors' elaboration.

territory. Finally, the fact that all circles are included within the same geometric shape shows that all tools contribute to the realization of the same project of personal well-being (Fig. 4).

A concrete hypothesis: the life project within the Tuscany Region organisational system

In the following section we examine the implications of applying the "mosaic strategy tool" and other aspects mentioned in the background section within the socio-institutional context of the Tuscany Region.

To put it simply, the current health and social care system welcomes users in a unique place where all information is collected: the *Punto Insieme* or *Punto Unico di Accesso*.[8] Subsequently, the user is

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[8] Unique point of access.

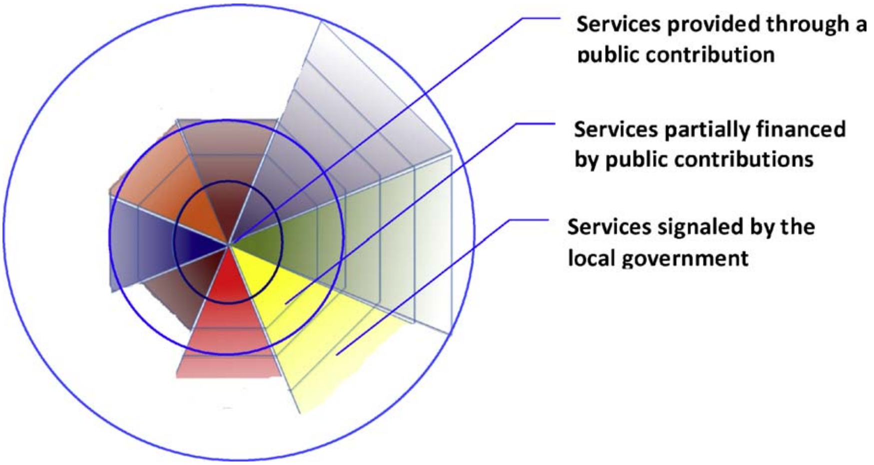

Fig. 4. The mosaic strategy as connection between the disabled person's needs and the tools actually available to satisfy them. Authors' elaboration.

placed by a micro-team or, in more complex cases, by a Multidisciplinary Assessment Unit, within one of the macro profiles which have been outlined partially following the ICF guidelines (Biggeri & Bellanca, 2011).

Our framework argues for the possibility for the person with disability to draft his/her own life project which complements his/her macro profile within the health and social care system. The combination of these two elements determines the process through which s/he is included within the community and territory where s/he lives.

Introducing the life project within the organisational model allows to focus on the person with disability and his/her objectives, providing the multidisciplinary team with further information that goes beyond mere medical data. In such a framework the person with disabilities develops a pro-active attitude, committing him/herself to reaching the goals defined in the life project. When mentally disabled people are considered, caregivers can also be actively involved (Bellanca et al., this issue). Furthermore, in these and other cases, it emerges the necessity to introduce a new kind of professional, i.e. the case manager. The objective of the latter, who is usually a medical practitioner, is that of accompanying the person with disability (and if necessary her/his family) in her/his customized pathway, supporting her/him in planning actions and activities. In order to be able to accomplish tutoring and coordinating tasks requiring considerable technical and relation skills, the case manager needs to be adequately trained.[9]

The life project can be introduced within the Tuscany system through a few organisational modifications, which do not require major changes of the current processes. Fig. 5 schematically represents the model of access and follow-up of the user with disability. In black we report the steps that, starting from the signalling phase, lead to the drafting of the programmes and the services provided by the health and social care system. We highlight our proposals for organisational modifications in grey: centred on the life project, we lay emphasis on the importance of a tailored approach.

The simplified model illustrated by Fig. 5 combines elements of the organisational model employed by the Tuscany Region for elderly and people presenting various forms of dependency with certain elements of the current model being used for providing support to persons with disability.

By following the main arrow as well as the smaller arrows representing the administrative tasks that need to be accomplished during the follow-up, it is possible to decompose the organisation of the system into six main phases.[10]

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[9] For a good practice of 87 cases of life project with case manager, see Bonfanti and Biggeri (2010).

[10] This pathway is partially inspired by the ideal typical one outlined by Toniolo Piva (2007).

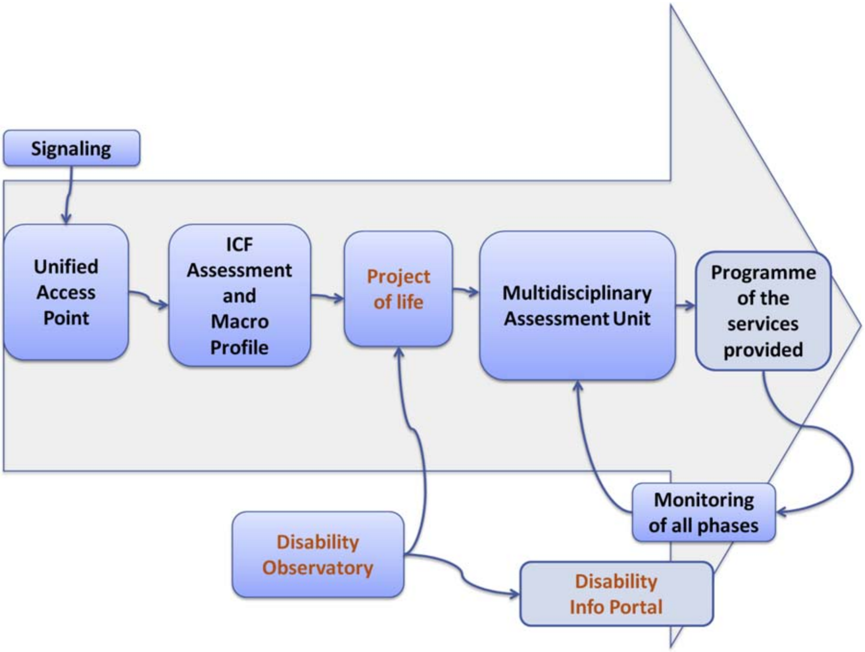

Fig. 5. Simplified organisational model after the introduction of the life project, the disability observatory and the disability info portal of the Tuscany Region.
Authors' elaboration.

The contact or signalling phase

The procedure starts when the person with disability case is reported by him/herself, referred by his/her GP, a caregiver or another actor of the health and social care system. The Tuscany system has been facilitating this operation thanks to the setting up of the Unique Points of Access, created in order to strengthen the ability to adequately address the various needs of the user. Indeed, the Unique Access Point represents an interface between the person with disability and the health and social care services, particularly since it has the function of coordinating the provision of services. It thus ensures:

- the collection of the registration forms;
- the activation of the multidimensional assessment;
- the scheduling of the Multidisciplinary Assessment Unit meetings;
- the summoning of the GP;
- the notification of the project to the user;
- the notification of the Multidisciplinary Assessment Unit's decision to conclude the procedure;
- the support for the monitoring of the resources available within the integrated system of health and social care services.

The technical assessment: the macro profile

Some interesting experiences, coordinated at the national level, have been initiated within the Tuscan organisational arrangement. Based on a simplified version of the WHO (2001) International Classification of Functioning, Disability and Health (Trani et al., this issue), known as ICF checklist, they aim at evaluating the needs of the person with disability on a smaller number of dimensions compared to the ICF complete version (Leonardi et al., 2001).[11]

Furthermore, four macro profiles of functioning have been created in order to determine the services according to the user's characteristics. The level of performance and that of capacity have been chosen as criteria to determine the specific macro profile a certain person comes under.[12] Based on the ICF assessment and on the four macro profiles, every person is evaluated within the different domains of activity and participation.

The life project

This instrument, as we already said, gives the possibility of elaborating an accurate mapping of the person's needs, characteristics, and desires throughout a personal process of elaboration. Therefore, the life project represents through the mosaic strategy the main tool that guarantees the demand for suitable services to the users. The overall end pursued by the Tuscany system through the provision of health and social care services should be compliant with the objectives described in the users' life project. Moreover, involving persons with disability in the choice of the interventions they require represents the best way to enhance their pro-active attitude, and thus develop their functionings. The life project can be elaborated through the establishing of a service of peer counseling (Barbuto et al., this issue).

The multidimensional assessment

The multidimensional assessment is a crucial phase within the overall process because it allows for the determination of services that respond to the nature of the person's demand in a comprehensive manner and therefore decides knowledgeably which domain of competence this response should come under. Additionally, this evaluation promotes a relation of mutual trust between the person with disability and the regional services; a relation on which the successful implementation of the shared project rests.

The Multidisciplinary Assessment Unit for disability is an organisation based on the evaluation of people who are not self-sufficient, as well as on the local micro-teams in charge of defining 'global rehabilitative projects' for persons with disability.

The Unit is expected to assess the citizen's complex health and social care needs. The response to these needs implies the involvement of a host of services, provided by a range of different structures. In other words, the Unit represents the basic comprehensive tool identified by health and social care services in order to ensure, at an operational level, the effective collaboration between district/departmental and over district services, hospital, residential and semi-residential services and the social services.

The overall objective is to improve citizens' health and quality of life through a global project, inspired by the life project proposed by the user and shared by the team, which avoids the implementation of fragmented interventions, taking into account the resources available within a given territorial network.

The Multidisciplinary Assessment Unit should consist of a fixed component and of a flexible one. The former should be composed of the Social and the Health Directors, the social worker from the municipality in which the citizen lives as well as the GP. The latter should include all professionals and workers that take care of the user (medical practitioner, psychologist, psychiatrist, nurses, health and social workers, occupational therapist, health educator, guardian or the sustaining trustee), alongside the citizen's or his/her family's representative (Bonfanti & Biggeri, 2010). Furthermore, if not

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[11] Although the introduction of the ICF within the Tuscany system represents a valuable progress since it provides information regarding the social and environmental dimensions in the person's life, this approach faces the limits and criticisms examined by Trani and colleagues in the first article of this issue.

[12] More specifically, when both performance and capacity are of a high level we have a 'supervision profile'; when they are both at a low level we have a 'redesign profile'; when performance is high but capacity is low we have a 'sustainability profile', and when performance is low and capacity is high we have a 're-modulation profile'.

overlapping with one of the medical specialists mentioned, the micro-team should include the case manager.

The programme of the public services provided

The fifth step of our pathway corresponds to the programme of the public services provided. After carefully examining both the life project presented by the user and the outcome of the evaluation carried out using the ICF checklist and the micro-profiles, the Multidisciplinary Assessment Unit for disability outlines a programme of the services that has to be activated for the benefit of the person with disability, specifying the amount and type of resources required. In other words, through the life project, the Multidisciplinary Assessment Unit is tasked with identifying the combination that best fulfills the user's needs and aspirations, among the various combinations of available services. While carrying out this operation, the Unit takes into account the ranking of services established by the policy maker (i.e. the concentric circles in Fig. 4). For instance, the Multidisciplinary Assessment Unit should ask the user to firstly choose whether he/she desires to prioritise the development of social relations or the dimension of mobility, and secondly whether he/she prefers to channel the resources at his/her disposal into interventions meant to improve his/her working skills, or instead, into activities which will improve his/her capacity of personal expression. The outcome of this negotiation process is the definition of a hierarchy of needs and of services to be implemented through a range of concrete actions, specified by a series of sub-objectives.[13]

The completion of the fifth step requires also a reform of the organisational structure on which the delivery of heath and social services is based towards the so-called matrix organisation structure (Bellanca & Bonfanti, 2011).[14] Such change aims at creating a person-centred network of services where several different professionals and workers collaborate to implement the life project of the person with disability.

The monitoring of the service programme and of the macro profiles

The monitoring process of the programme of services is very important as it represents a control tool and, if required, an opportunity to redesign the programme of services (i.e. measurement issues and some form of evaluation are concerned). Indeed, because disability is a dynamic process and because people's needs change according to their age, stage of life and achievements in different domains, the services provided have to be constantly monitored and updated at crucial stages, such as childhood, the shift from adolescence to adulthood and during different periods in adulthood.

The monitoring process necessarily concerns all phases of the follow-up. In fact, it must guarantee the revision of the technical evaluation and of the life project, enabling to draft a new programme of services. As a result, with time, the monitoring process enables the consolidation of the relation between users and services. Moreover, it ensures the adaptability and the flexibility needed to face the changes in the lives of persons with disability, as well as the introduction of new rehabilitation techniques as and when required.

The informative system: the Tuscany Region disability information portal

Facilitating the access to services and the communication between policy makers and service users represents one of the priorities pursued by the Tuscany Region, in accordance with the capability framework. It is undeniable that an increase of the information available expands opportunities for persons with disability. Such considerations have enabled the setting up and development of the above described Unique Points of Access. These useful instruments of access and administrative management

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[13] An open issue regards the presence or not of a non-negotiable part, i.e. those that are essential for any human being.

[14] As argued by Toniolo Piva (2007), the "matrix model" represents an approach that, while not supposing the existence of an institutional unity, is able to manage the complexity generated by work based on projects carried out by professionals belonging to different services connected through a network.

might be enhanced by functional and economical tools, such as web information portals and electronic medical records, in order to further facilitate users' access to services and the exchange of information between users and welfare/health staff.

Creating an informative network about disability, accessible through a web portal, would promote information sharing among stakeholders, thus filling a gap identified by interviewees during the fieldwork we carried out (Biggeri & Bellanca, 2011).

An effective flow of information has to be bilateral. However, what currently happens is that, on one hand, persons with disability find it difficult to obtain information concerning access to public services and interventions, while, on the other, they spend a considerable amount of time repeating information to the different medical practitioners regarding the 'history' of their disability.[15] In turn, each medical specialist has to note down everything from scratch, thus unnecessarily protracting the examination with a cost for the overall system in terms of efficiency and effectiveness.

A complete informative system based on a web portal should have three main goals.

The first one is to inform users and specialists about a host of aspects: legislation, medical centres, events, associations, therapies, facilitations, pathways promoting integration and so forth.[16] The second aim is that of informing the regional system about disability issues in a dynamic way: statistical data, kind of disabilities, diffusion of specialised centres and associations, etc. All stakeholders must be able to register at the portal, to provide personal data in an adequately protected manner. Such a registration process would guarantee the access to a larger amount of information and, above all, the possibility of interacting with other users with similar needs and/or interests. For instance, people with the same kind of disability living in different areas of the region could compare their therapies and service programmes, potentially identifying ways of improving their well-being. Finally, the users' registration, together with the facility of promoting on-line surveys through the portal, would allow the system to register relevant quantitative and qualitative data in an economical and effective way. Finally, the third objective is to strengthen a private and public disability network of associations, medical specialists, self-help groups, open forums about technical issues, etc. Indeed, a considerable limitation to the social integration of persons with disability is their isolation and the effects thereof. By contrast, the very presence of a disability increases the person's need of belonging to a network of people or associations, which facilitates the processes of social inclusion and enables the user to access public and private services, on an informed basis. This in turn encourages the strengthening of the network and, consequently, the creation of groups and associations connected at the territorial level.

The Tuscany Region has also been testing the electronic clinical record responding to four main needs: improving the information quality and filing; reducing the length of user's examination; promoting an accurate exchange of information about the user's background, thus facilitating the professional's work; encouraging users and practitioners to note down all health and social care interventions in which the person with disability has been involved.

The disability observatory

The disability observatory represents the operative tool necessary to start up the innovations mentioned above and, subsequently, to promote the efficiency of the reformed system.

Within the observatory, the establishment of which has been planned by the Social Affair Department of Tuscany Region for a long time, should converge different skills in order to improve the informative system and, at the same time, to guarantee peer support[17] to the counselors working

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[15] While initially such a process might have a therapeutic value, over time it turns into a very stressful, tiring, at times humiliating, exercise, which makes the service-user relation even more difficult.

[16] The information disability portal of the British government (http://www.direct.gov.uk), whose slogan is 'all services in one place' seems to be particularly effective in achieving this goal.

[17] The peer supporter working within the observatory would have the task of voicing, listening to and updating the different territorial realities, receiving the demands coming from the existing associative structure. In this perspective, the observatory would promote the strengthening of the overall regional system by valorising micro-level experiences.

within the Tuscany territory.[18] These counselors are persons with disability or caregivers (Barbuto et al., this issue) who, after having received adequate training, are able to support the user during the drafting of the 'life project' and the evaluation carried out by the Multidimensional Assessment Unit. In addition, they might improve collaboration with institutions such as schools, universities and other public or private centres, in order to enable these to take into account the needs of persons with disability in a relevant and systematic manner.

More specifically, the disability observatory/platform has three main objectives: first, to introduce and advertise the disability info point[19]; secondly, to test of the peer support and peer counselors' role within the Tuscan organisational system; and finally, to introduce and promote the life project within the Tuscan organisational system.

With regard to the introduction of this innovative tool, it is necessary to bear in mind that such an initiative might face several structural resistances. Therefore the life project has to be introduced gradually, step by step, and as an outcome of a participatory process in which all stakeholders, especially persons with disability, are actively involved.

To conclude, we strongly argue that the observatory will bring considerable advantages for the users and their caregivers, as well as for the region and the local governments. As far as users are concerned, the main positive aspects is a facilitated access to relevant information, a reduction in costs, time and energy, an overall reflection on the life project and a continuous and qualified support. The advantages for the Region and the local governments would be a more significant impact of public expenditure on the well-being/well-becoming of disabled people, their families and their communities, with more synergies between services and a reduction in transaction costs.

Conclusion

A political reform which claims to enhance people's well-being in an effective and efficient way must focus on the opportunities that are accessible to them and, above all, on their potentialities in order to design public policies that are more tailored and equitable (as defined by Sen in his latest book 'The Idea of Justice') (Sen, 2009a). This requires a cultural shift by political leaders and the willingness to enable all citizens to take decisions as active agents of change rather than as passive recipients of medical care.

In this article we have argued that, drawing on Amartya Sen's capability approach, the key elements of the revision of the welfare policies for disability in Tuscany consist of: the life project, the mosaic strategy, the disability observatory and, within the latter, an institutionalised system of peer counseling. The overall goal of our proposal is that of achieving the shift 'from cure to care'. Such change should rest on the possibility of drafting a personal life project which, complementarily to the definition of the macro profiles by the Multidisciplinary Assessment Unit, provides a wider and more accurate mapping of the characteristics of the person with disability and thus, of the services required to promote his/her well-being.

It is worth stressing that the elaboration of the life project requires that the person with disability, or, in case of severe mental illness or intellectual disability, his/her caregivers undertake an individual process of awareness and empowerment alongside the development of a proactive attitude.

Finally, it is important to emphasize that in order to favour personal and collective flourishing, a reform of social policies for people with disabilities has to be complemented with a structural reorganisation of the delivery system of health and social services, and with an up-grading of the overall level of competencies but, above all, with a well-organized and capillary informative system.

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[18] Each health and social care territorial district of the Tuscany Region should hire at least one peer counsellor in its disability staff.

[19] The disability observatory is expected to collaborate with the different levels of local government, as well as with all health and social care territorial districts and associations. Furthermore an informative coordinator and a portal webmaster will work within the observatory.

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