

New mode of care. Value and limit of the person-centered care planning for people with mental disability

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Abstract

The huge increase of people with mental and intellectual disability worldwide, and the advocacy capacity achieved by these patients, which culminated in the Convention on the Rights of Persons with Disabilities (CRPD), came along the shifts in the way governments deliver public services. In particular, in the last decades, many countries examined how to provide a person with disabilities an acceptable social functioning, improve well-being, according to the principles of equity, solidarity and participation. A new political and social-health model was born, called “welfare community”, users are protagonists of their health project and the resources put in place assume an investment character on the community and its economic development. Personalisation of social and health services is also considered in many countries as a “new mode of care”, although in different forms depending on financial aspect and recipients. The present article is a narrative review that examines and summarize international research and non-research material to survey the different implementation strategies of personalisation in different countries, with a special focus on Italy, in attempting to provide conceptual clarity about this topic in terms of opportunities and pitfalls.

Key words

- personalisation
- community
- welfare
- health
- social
- care
- mental disability

INTRODUCTION

The World Health Organisation estimates that over 1 billion people globally experience disability (15% of the world's population) and that this number will continue to grow into the future, with the consequent challenge of giving appropriate answers to the increase in people's needs [1].

In 2013, in Italy, in line with the last data reported by the National Institute of Statistics (ISTAT), about 13 million people aged 15 and over have serious functional limitations, disability, or chronicity. Among these, 23.4% (about 3 million people) report having severe limitations, i.e. the maximum degree of difficulty in at least one of the motor, sensory, or essential activities of daily life [2].

The impact of this health problem in terms of financial cost, morbidity, and need of care is so high that over the past 30 years there have been major shifts in the way governments deliver public services. Increasing complexity and cost of care have stimulated the planning of integrated healthcare services with the aim of coordinating the delivery of care and reducing waste and burden on the system [3]. At the same time, many countries have deliberated welfare solutions in accor-

dance with the principles of the Convention on the Rights of Persons with Disabilities [4], and they shared the concept that “disability is the result of a complex relationship between health conditions, environmental and personal factors in a dynamic interaction between these elements that can mutually change”.

As a result, at the beginning of the last century, models such as welfare community and personalisation call attention to the effectiveness of the system rather than on its efficiency, to grant social answers to the needs of people well off or with severe social problems or disability.

The welfare community model emphasizes the role of the local community and introduces innovative strategies for health systems. The main elements of this innovation are decentralized services, person-centred care, a stronger link between governments and people, and the promotion of a partnership between the community and people with needs in order to increase the spectrum of supports available and to empower and advocate people with needs for more advanced health and social reforms in respect of their rights [5]. Finally, the welfare community could be the best “place” to play democracy and participation and thus to give substance to the Am-

arytha Sen' capabilities approach [6]. This new mode of giving health and social care is able to improve the freedom of choice of persons and families towards institutions and transform the costs of care and assistance in productive investments that increase social innovation and satisfaction for people and families. Users become protagonists of their health project, and the resources that are put in place assume an investment character for the community and its economic development. This model of welfare differs from welfare based on efficiency, which meets the needs of users and provides answers in the form of pre-ordinate assistance services. In turn, by the "personalization of services", community welfare allows the citizens to be involved in the production process of the service itself, guaranteeing their active participation and stimulating the community to base itself on the values of solidarity, social cohesion, and the good common [7-10]. Personalisation assumes in this framework a pivotal role in the future of the welfare state, as this model appears to increase the value of individual's choice and autonomy in care systems, and proposes itself as a social determinant of health [11]. The concept of personalisation, embedded in the welfare community model, claims for services tailored to the needs and preferences of citizens, and promotes recovery and inclusion. The overall vision is that the state should empower citizens to shape their own lives and the services they receive [12]. In this context, people are granted the power to design the most useful services to meet their specific needs and are an active part in the decision-making process, responsible for their plan, and likely self-directing monetary benefit, with powers of speech and criticism of the service itself.

The aim of this paper is to explore the concepts characterizing the personalised care model through the literature, and the spread of policies that at international and Italian level apply "personalisation" and self-direct support in their welfare strategies.

METHOD

Research and non-research material was examined and summarised by a narrative review to provide conceptual clarity about the topic of the paper.

The following literature search strategy was devised in order to collect the relevant material and ensure adequate methodological rigour:

- electronic database search (PubMed, Google Scholar);
- relevant content of the websites of the Italian Regions;
- grey literature (institutional, charity, or specific welfare programs reports).

The search included the following terms: person-centred care, personalization, personalized plans, individual budgets, personal budget, direct payments, personal health budget, social budget, health budget, person-centred budget, and self-direct support.

We have intentionally excluded specific terms describing the target population of these programs (older people, children and adolescents, elderly, end-of-life care, people with disability, drug users, people with chronic and chronic degenerative, HIV patients, etc.) to collect the wider bibliographic references on specific

and comprehensive welfare programs that implies a personalisation approach.

We also examined the reference lists of selected articles to identify other useful articles and to scan topics in order to overview the countries' policies on "personalisation" and the benefits and drawbacks of personal budgets, especially for people with mental and intellectual disability, in order to highlight specific pitfalls or opportunities of personalisation for these particular groups in need.

In this narrative review, we tried to summarize the available knowledge on the topic. Given that our interpretation of the literature is affected by our personal convictions, this review might be biased to some degree.

FINDINGS

The main topics that emerged from the narrative review of the literature are summarized here.

Personalisation

In person-centred models, personalisation is the way to have choice and control on welfare solutions. This includes giving funds for the assistance directly to users (direct payment), so they can purchase services and supports or in some case make new ones that best meet their needs, rather than standard "one size fits all" programs [13, 14, 11]. Depending on country or administration, these welfare strategies are called with different names, such as "health budget", "personal budget", "direct payments", "individual budget", "personal health budget", "social budget", "person-centred budget", "self-management model", "independent living fund", and "integrated care" [15]. They may include the following main administrative funding channels: local authority adult social care; integrated community service; people for housing-related support; access to work; independent living fund. Therefore, in this context, the term "personalization" has nothing to do with the concept of "personalised treatment" as it is used in the clinical literature, which refers to the identification of predictors of treatment success in order to apply specific psychopharmacological or psychosocial interventions only to the patients known to benefit especially well from these interventions [16]. The most frequently used strategies to support person-centred care budget are the following ones:

- the local authority places an individual's personal budget with a third party, so that day-to-day business arrangements are between the service user who has a personal budget and the third party provider (purchasing or commissioning);
- the local authority itself holds the personal budget and manages/arranges the services on behalf of the service user (providing in-house owned or managed services);
- a mixed solution including elements of the previous ones;
- direct payment, i.e., people are given the cash to buy the services that they and their doctor or – care manager decide they need. People have to show how they have spent the money, but they buy and manage services themselves.

The introduction of ‘personalisation’ identifies the (personal) health budget as the ideal tool for the activation of integrated social and health interventions defined by personalized life projects. It is an allocation of funds to users to support directly their individual health and wellness needs, which is planned and concerted between the individual and the health and social services, often through a professional, such as the care planner or manager [15]. Then, the health budget states the centrality of the person and its role in the co-construction of the individual projects that result in the definition of a contract. Some authors have underscored the need of a reflection on the different meanings that personalisation can assume when operational processes are applied. Personalisation is proposed as a distinctly different concept from that of individualisation [17, 18]. On the one hand, the services that operate according to individualisation provide services tailored to the user, specifically and individually for him or her. In this model, the administration has the role of enabling citizens to “purchase” services that best meet their needs from a “service market” [10]. Thus, the provision of eligible services is often within a pre-fixed range, with the risk that the choice concerns how services can be used rather than the purpose of their use and the outcome they want achieve [19]. In individualisation models, the users are passive because they are not recognized as being able to co-plan and/or co-product the service. On the other hand, in greater agreement with a community welfare model, personalisation is conceived in a participative framework, where people who use the services not only choose and control the services necessary for their needs, but also contribute to producing them [20, 21, 3]. In this perspective, the model of governance changes, as the public authority no longer only provides fees for services but it actively programs and calls all the protagonists (person, family, associations, communities, volunteering) to be co-producers and co-responsible for the well-being of the people who express a health need [18]. Thus, personalisation offers a new way and a potential improvement of the supports for the individuals with care needs. Furthermore, such a model of person-centred care might result in significant changes for several different agencies and individuals involved in the design and delivery of welfare services [8, 17].

International experiences

The approach to personalization and its different application strategies has found several implementations at the international and national level as part of the ongoing evolution of welfare systems worldwide, with significant variation in the degree of patient choice and control [22]. In addition, the contexts in which the different programmes are developed differ in many ways, i.e., structurally, organisationally, and culturally. Thus, personalisation is differently shaped in different countries by how they set different categories of services (continuing healthcare, long-term health package, caregivers supports) between e.g., health care and social care. Comparing key aspects of different programmes, such as eligibility criteria, scope, and the ways in which budgets are planned, deployed and monitored, is of par-

amount importance. However, for the sake of brevity, we present here only a summary of the main international experiences about social and health policy. For a more complete review of international experiences, we refer the interested reader to Alakeson [23] and Wirrmann Gadsby [15]. A more detailed description will be devoted to the Italian experience.

USA

A “consumer-directed care programme” funded by the Medicaid Personal Care Services was firstly experimented in the USA during the 1970s. Rather than being implemented nationally, this benefit option was implemented under the purview of individual states and was addressed to low-income elderly and disabled people. The model comes out of the independent living and disability rights movements, and it initially included mainly services such as home and community-based long-term care [24]. The more flexible Cash and Counselling Program started in the 1990s, and was defined as “an approach to long-term care personal assistance services in which the government gives people cash allowances to pay for the services and goods they feel would best meet their personal care needs” [25]. The main objective of this programme was to enable people with disabilities to decide for themselves the type of social and health service, which completely overturned the traditional model where the decision on the type of intervention to be provided was delegated to the professional [26]. Initially implemented only in fifteen states under Medicaid provider, the number of states in which it is available has now been expanded considerably and relies on non-Medicaid insurance or non-profit assistance agency. In the Cash and Counselling Program, recipients were given the flexibility to choose their own home care agencies, and family members could act as a “home care agency”. This meant that relatives, such as the adult children of aging parents, could be hired and paid for the personal assistance they provided. In other words, family members could become paid caregivers [27]. Designed specifically for in-home care, some programs currently include individuals who lived in small group homes and even assisted living residences.

Canada

Programs called Self-Managed Attendant Services – Direct Funding have been run for two decades in Canada [28, 29]. In contrast to conventional programs in which care is managed and delivered by professionals or agencies on behalf of the client, in self-managed care governments directly fund clients, who then purchase services from providers of their choice. The clients have an active and central role both in defining needs and in determining how those needs should be met. However, this programme is not equally widespread in Canada, and the available programs differ widely in terms of patient eligibility and structure. Ontario, for example, offers the largest self-directed care program in Canada, managed by Self-Directed Personal Support Services Ontario [30]. It concerns people with high-need conditions requiring at least 14 hours of support per week (mostly families with autistic children as well as for

some seniors and persons with disabilities), who select and schedule their own personal support workers. The Ontario Ministry of Health and Long-Term Care and Local Health Integration Networks (LHINs) has also implemented a new self-directed care program, named Family-Managed Home Care, under which clients or their decision-makers will receive funding to purchase home care or employ care providers. Other provinces that have some form of self-directed care include British Columbia, Alberta, Manitoba, and Saskatchewan. Finally, Canada launched in 2010 a specific program devoted to people with mental illness. The Mental Health Commission of Canada launched this program to address the multifaceted problems affecting mental health system in the country. The driver assumed by the Commission as transforming mental health system was the development of a 'recovery' system (resuming life in the community with dignity and purpose, lived at the individual's full potential) based on a mental health self-directed care model [31].

United Kingdom

In the UK, personalization was introduced in the 1980s by the pressure of disabled people's organisations. In the 1990s some local authorities applied the concept of personalization by introducing "direct payments" (a cash sum to replace the services provided directly) intending to provide physically disabled adults with more choice and control over their lives. In 2003, the Department of Health in England promoted a pilot program called "In Control". People with disabilities are given a budget and establish what level of control they wish to take over that budget; then, they decide how to use it and seek approval from local authorities. People can use their budget flexibly, as they can use statutory services (the cost of which is taken out of the budget) or other forms of support; if they change their minds, they can redirect their budget toward other forms of support viewed as more appropriate. This pilot experience showed that people had an improvement in outcome when given the opportunity to get involved in their own evaluation and intervention plan. The pilot experience initially involved a few local authorities, but after preliminary results suggesting its effectiveness and its potential for saving money, in 2008 it was extended to all the local authorities concerned [19]. The individual budget can either be administered by the users or their family as a direct payment, or it can be managed by the local authority or a third party to which the service is commissioned. The money may be used to support the person's well-being, social inclusion, self-management, and participation in meaningful activities. The assumption of personal budgets stands at 88 per cent of people with disabilities aged under 65, with 42 per cent of these taking the money as a direct payment [32]. The Care Act in 2014 [33] reaffirmed the concept of direct payments, individual budgets, and self-directed support (SDS) as useful tools to empower all disabled persons to obtain a support that is tailored to their needs [34, 12]. In 2014, the Scottish Government introduced an innovative self-directed support (SDS) that helps people and families to have an informed choice on how to use the budget

according to their needs by a co-production approach, i.e., support that is designed and delivered in equal partnership between people and professionals [35]. As for Ireland, a National Disability Strategy was launched in 2004 by the National Disability Authority [36]; its main aim is to support the inclusion of people with disability in the society by the elaboration of standards and guidelines that drive person-centred planning. Recently, the Ireland's Health Service Executive launched a reform called Transforming Lives Program with the following three main points in agenda: 1) congregated settings (a time to move on), which is about enabling people to "live ordinary lives in ordinary places" and aims to enable disabled people to move from large institutions (congregated settings) to their own homes in the community with the support they need; 2) the provision of day services (new directions), which aims to set the standards for a new approach to adult day services to be based on person-centred planning [37-38]; 3) progressing children's services (0-18 therapy services).

The Netherlands

In the Netherlands, personal budget (Persoonsgebonden Budget, i.e., PGB) was institutionalised in 1995, after a trial period that started in 1991. Initially it was reserved for specific groups of people, such as those who needed home help or nursing, and people with mental retardation. It was later extended to disabled children. In 1997, it became possible to employ one's own husband or wife.

The personal budget aims to give autonomy and empowerment to the patients. It should also promote competition between providers, increase efficiency, improve the quality of care, and strengthen the role of patients as consumers, rather than only as citizens. As consumers, patients get a stronger voice in both care politics and the organisation of care. Nevertheless, as the market is very bureaucratic, it was necessary to enter a new professional figure, the care consultant, who is paid by the state to help the budget holder. This, in contrast to the goal of stimulating people's independence, carries the risk of making the patient dependant on the care consultant [39, 40].

Germany

Cash payment for care was introduced in 1995 and expanded in 2008. The primary motivation was to increase independence and freedom of choice of individuals by expanding the options available for home and community-based long-term care, increase competition, reduce pressure for care homes, and thus lead to lower costs. Eligible people are "persons with physical, psychological or mental disease or handicap that are expected to need a substantial amount of help to carry out the routine activities of everyday life for approximately six month or more" [41]. It is used to nursing, assistance at workplace, transport, and other services provided by health/care insurance.

Norway

Since the 2000s, Norway has adopted a new model of organization of the social services that strengthens

the role of the consumer among users, by offering people an allocation of funding to meet their needs. Furthermore, the personalisation policies encourage greater choice and control regarding care services and allow for the use of “cash-for-care”, which gives people an allocation of funding to meet their needs. This cash-for-care system is called user-controlled personal assistance (Brukerstyrt Personlig Assistance, i.e., BPA) [42]. Within this model, the Municipality evaluates the eligible persons, and the user assumes the role of employer/manager with or without the support of the municipality or of cooperatives. Central to this model are the employment and choice of the user’s care workers, and the decisions about their working tasks and their time of working [43]. Similar programs are developed in the other Scandinavian countries [44].

Australia

The Australian National Disability Insurance Scheme (NDIS) was introduced in 2013 and rolled out in 2016. The reform arose as a response of the government to reports that Australia was the worst performer of 27 nations in terms of poverty levels for people with disability [45]. The NDIS is a population-wide insurance-based scheme that includes services for several categories of people with disability, including psychiatric disabilities. There have been established personalized funding whereby eligible people choose the services that they need to help them to live well, and funds are then allocated according to a “personal budget” to be used to pay for services under normal business arrangements, replacing a patchwork of state-by-state prerogatives [46]. The main objective is to support the social and economic participation of people with disabilities; also, the programme aims at increasing “men at work”. This scheme intends personalisation as social investment that transfers fiscal commitment that the reform needs in social and human capital in order to enhance global competitiveness (Needham and Dickinson, 2018). However, since 2012, the Australian government set up a series of reforms and phased in a universal delivery of “Care package”, which was formalised in February 2017 under the Increasing Choice in Home Care policy [47]. Consumer-directed care is here defined as when “you (and your carer) have more choice and control over what services are delivered and where and when they are delivered” [47]. The aim is to give patients greater freedom of choice by providing them with the opportunity to decide about the provision of their health care.

Italy. The social and health integration policy

In Italy, the first steps towards a policy of social and health integration started with the reform of the National Health System [48] and the DPCM February 14, 2001 [49]. Article 3 septies of Decree-Law 229/1999 defined social and health services as: “*all activities aimed at satisfying, through integrated care pathways, the health needs of the person that requires unitary health services and social protection actions, capable of guaranteeing, also in the long term, the continuity between the care and rehabilitation actions*”. The same decree divided the social and

health services into health-related social service (health promotion activities, prevention, and removal of invalidating pathologies) and social-related health service (support activities for the person in need). Thus, since 2001 the Italian National Health System recognised the close correlation between health and social services, which must satisfy the multidimensional needs of citizens (health, social, relational, and economic needs). To the services already identified, it added the health and social services with high health integration, i.e., services in which health and social aspects are closely linked. In addition, by the Law 328/2000 [50] “Framework law for the realization of the integrated system of interventions and social services”, Italy introduced the personal plan as integration of social and health care. This reform increased the leading role of the local institutions and civil society. Furthermore, it specified that social and health integration should be the “synthesis of the economic, professional and human resources necessary to start a process aimed at restoring the person to an acceptable social functioning, through an individual rehabilitative therapeutic project, produced and participated by the patient, his family and its community” [51, 10, 9]. It is important to highlight that in Italy, in the field of mental health, the idea of integrated care was previously defined in continuity with the legacy left by Franco Bagaglia by the Law 180/1978 [52]. This law enforced the closure of the mental hospital, which restored dignity to people with mental problems, and promoted the role of the therapeutic community within an “ecological” perspective. This innovative reform imprinted in the Italian society a new direction in the mode of care, and encouraged a higher level of integration between social and health care [53].

In planning the integration of health and social services, one has to rely on every area of human daily living and more recently an interesting application has been given with the approach of the quality of life (QoL) [54]. The main areas are: 1) learning/communication; 2) training/work; 3) home/social habitat; 4) affectivity/sociability [9]. The Individualized Therapeutic Plan [55] builds on these areas and relies on a tailored financial support to make on a “personal health budget”. A wide spectrum of people is eligible for the health budget, such as persons with disabilities, both physical and mental, in either acute or chronic condition; ex-prisoners and drug users; or, more generally, people with social marginality and exclusion for whom the rehabilitation process must include both health and social aspects. All this requires a strong integration of human and financial resources to support autonomous life by creating an articulated network of agents that involves both public sector organizations and private actors, including the person and his family, local health units, municipalities, and voluntary and charitable organizations. The health budget assumes different intensities according to the health condition and level of social functioning of the patient [51, 9, 56]

Because of health reforms that in Italy have established the importance of integration of the health and social services, some regions have adopted the health budget as an integrated tool for managing social-



Table 1
Italian regional health and social integrated care programmes

Region	Target population	Use	Operative tool			Financial / funding tool		Co-design	Regional law
			PUA	UVM	PTI/PAI	BdS	Voucher		
Piemonte	Psychiatric patients		x	x	x	x		x	DGR n. 29/3944 del 2016, DGR n. 41 del 2018, DGR n. 355/1817 del 2019 – “Piano d’Azione per la Salute Mentale (PASM)”
Lombardia	Psychiatric patients, fragile people, persons with very serious disabilities (i.e. ALS, vegetative state), persons with severe disabilities and reliant from other persons, persons with disabilities	Affection/ socializing Training/work home/social habitat	x	x	x	x	x	x	DGR n. 7/12902 del 2003, DGR n. 23 del 2005, DGR n. 79156 del 2008, DGR n. 10/74027 del 2013, DGR n. X/7600 del 2017-Regole 2018
Veneto	Psychiatric patients, fragile people, disabilities (i.e. ALS, vegetative state), persons with severe disabilities and reliant from other persons, persons with disabilities		nd	x	x	nd	nd	x	DGR n. 2372 del 2011 LR 23 del 2012 DGR 975 del 2013
Friuli-Venezia Giulia	Families, minors, elderly, end-of-life care, people with disability, drug users, people with chronic and chronic degenerative, HIV patients	Living Training/ working Socializing	x	x	x	x		x	LR n. 6 del 2006, art. 5 (progetto assistenziale personalizzato) art. 41 (Fondo per l’autonomia possibile)
Liguria	People with fragility condition, not self-sufficiency		x	x	x	dote di cura		x	DGR n. 446 del 2015 - Sistema integrato socio-sanitario disabilità
Emilia-Romagna	People with mental disorders temporary Project on fragile people	Home/habitat Affection/ socializing Training/work	x	x	x	x		x	DGR 478/2013; DGR 805/2014 DGR 1554/2015 “Linee di indirizzo piano sociale e sanitario Emilia-Romagna 2017-2019”
Toscana	People with disability	Health and social, school and work, environmental / domestic and socio-relational	x	x	x	x			DGR n. 1449 del 2017
Lazio	Families, children and adolescents with disabilities, people with disabilities, elderly, migrants and other minorities, disadvantaged people, prisoners, homeless people, psychiatric patients, drug users	Learning/ affection/ socializing training/work home/ social habitat	x	x	x	x	x	x	LR n. 15 del 2016 LR n. 11 del 2016 -Sistema integrato degli interventi e dei servizi sociali della Regione Lazio, art. 53 e capo VII DGR n. 326 del 2017 - Linee guida in materia di co-progettazione, DRG n 149 del 2018, DGR n. 259 del 2018 - Vita indipendente

Continues



Table 1
Continued

Region	Target population	Use	Operative tool			Financial / funding tool		Co-design	Regional law
			PUA	UVM	PTI/PAI	BdS	Voucher		
Campania	People with mental disorders, social disability, and chronic or degenerative disease	Learning/affection/ socializing Training/work Social habitat	x	x	x	x		x	LR n. 11 del 2007, LR n. 1 del 2012 art. 46, DGR n. 483 del 2012 - Linee Guida, LR n. 5 del 2012 (art. 3 agricoltura sociale) LR 7 del 2012 DGR n. 478 del 2013, DGR n. 805 del 2014
Sicilia	Psychiatric patients Non-self-sufficient elderly Persons with disabilities	Learning/affection/ socializing Training/work/ income Home/social habitat	x	x	x	x	x	x	GURS n. 24/2012- Piano Strategico Salute mentale GURS n.32/2017-Piano Regionale socio sanitario GURS n. 53/2002-Linee guida per l'attuazione del piano socio-sanitario, GURS n.30/2005- Definizione dei criteri per l'erogazione del buono socio-sanitario a nuclei familiari con anziani non autosufficienti o disabili gravi Agreement Protocollo di intesa tra Ministero Salute e Regione Sicilia sull'agricoltura sociale (21/02/2014) Legge n. 17/2019 art. 24
Sardegna	People cared for by mental health services (social disability or fragility), including drug users	Affection/ socializing training/work home/social habitat	x	x	x	x		x	DGR n. 35/6 del 2007 e allegato, DGR n. 10/24 del 2010 e allegato, DGR n. 50/19 del 2015 e allegato, DGR n. 26/5 del 2018 e allegato

Italian definitions and acronyms legend: PUA: single point of access; UVM: Multidimensional assessment unit; PTI/PAI: Personal therapeutic plan/personal assistance plan; BdS: personal health budget; Voucher: direct payment; dote di cura: personal health budget; DGR: Regional Council Law; LR: Regional Law; GURS: Official Journal of the Sicily Region.

health interventions. *Table 1* shows the main operational, financial and legislative measures implemented by some regions. The areas of application are mainly in the field of mental health (Lombardia, Piemonte, Friuli-Venezia Giulia, Liguria, Emilia-Romagna, Toscana, Lazio, Campania, Sardegna, and Sicilia) and disability (Friuli-Venezia Giulia, Lombardia, Toscana, Lazio, Campania, and Sicilia), but there are also practices in other fields of fragility, such as older people, drug users, child protection, and people with chronic degenerative diseases (Lombardia, Veneto, Friuli-Venezia Giulia, Emilia Romagna, Toscana, Lazio, Campania, and Sardegna). Common objectives include supporting active and autonomous life, stimulate the inclusion, and promote independent living. In some regions (Friuli-Venezia Giulia, Lazio, Campania, and Sicilia) health budgets have also been applied to social farming. Also, in a number of regions the health budget is provide by means of direct payment (Lombardia, Lazio, and Sicilia), which consists to provide vouchers through the local health units or the Municipalities. In this case, the economic contributions can be used

to buy assistance services in public or private, profit or non-profit subjects and are independently managed by the users under the assumption that they have all information necessary to choose the best service for them. To detail some applications of the regional legislation, *Table 2* summarises programs adopted by local health units in order to implement health budget and personal plan design.

Benefits and drawbacks of personal budgets

The welfare system must deal with the current high unpredictability of economic systems and the recurrent crises that have characterized the last decades. In this new context, as introduced above, the welfare system turns towards the notion of social investment where, instead of social assistance, capacitation of social and economic capital are the main effects of the welfare costs. In order to reach sustainability of welfare, there is a need of capacitating people by means of social services, thus transforming their abilities into positive resources to generate a cohesive and dynamic society [56, 57]. This increases human and social capital, and

Table 2
Some applications of socio-health integration policies in Italy

Local health unit	Objectives	Governance structure	PTRI (Italian acronym for Personal therapeutic rehabilitation plan)	Professionals involved	Case manager	Agents	Financial tools
Torino (TO4 district)	Reorganization of psychiatric residency, appropriateness of hospitalizations, and organization of the home care model (oriented to the health budget model) Overcoming the use of control techniques Participation of users and their family members in the Construction of Care Project (Piedmont Mental Health Plan, 2019)	CPI (Italian acronym for Individual Project Commission) composed of Mental Health Units professionals, which supports the teams of the CSM (Italian acronym for Mental Health Centre) in preparing individual residential, home, and integrated community support projects UVM (Italian acronym for Multi-dimensional Assessment Unit, which evaluates the project, assesses the clinical appropriateness, defines the resources, establishes the level of intensity, and identifies the co-producers) Assessment tools GAF: psychological and adaptive functioning Mini Icf-app: functioning and disability HoNOS: for efficacy evaluation Recovery Star: to measure progress	PTRI assessed by UVM Objectives: •social habitat •work •socializing	UVM Fixed members: President (appointed by the Director of the Complex Structure), psychiatrist, case-specific staff members, patient Variable members: defined by the President of the UVM in agreement with the patient (representatives of Local Health Units, of the social worker's units, and/or other public bodies of the patient's informal network, associations, third sector, any other person useful for carrying out the project)	Professional of the patient's referral team	Social and business agents chosen from a public call for tender	Co-participation of the Municipalities to the health budget
Pordenone	Welfare community: promotion of a network that integrates social-health resources with those of the territory Continuity in the transition (through services from childhood for adulthood) Construction of adult life projects in a community context.	Social health head office: governance and management Transition Unit assessment/diagnosis, transition planning; highly complex interventions (e.g. challenging behaviour); interventions for the construction of a network (e.g. job inclusion) Assessment tools -BasiQ: generic QoL scale -SPAID: psychiatric traits HoNOS: functional assessment Disabled advanced medical assistance (DAMA) dedicated access to hospital diagnosis and relationships with general practitioners (GPs) Multidisciplinary team for the handicap (Italian acronym: EMDH) personal plan definition, assignment of interventions and responsibilities, approval of the funds	Three dimensional PTRI: • to be (who the person is); • to belong (relationship with other people and environment); • to become (what the person does and what he or she would like to become)	Transition Unit Social workers, neuro-psychologists (specialist in neurodevelopment disorders), social educators, occupational therapists, dedicated psychiatric and neurological counsellors, professional dependent on social-health office EMDH: GPs, professionals of the health district, professionals of the Municipality social service, users, families, and other specialists (e.g. psychiatrist, neuropsychiatrist, psychologist, etc.)	Psychologist or educator (to design the plan). Social worker and EMHD (to realize the plan)	Accredited or community agents (cultural, sports, voluntary associations, social agriculture network, etc.) interventions/actions have to be activated according to the definitions given in a Local Health Unit list of interventions Public Health services (local health unit care, primary, specialist and hospital care) if defined in the project	Regional funds (for residential, semi-residential, and work integration services) Regional Health Fund (to the coverage of major health interventions). Funds of the municipalities social services (to personalized educational interventions on the territory) Fondo per l'autonomia, i.e., Autonomy Fund (to customize projects to support independent living and home care)

Continues

it avoids “dependence trap” and social isolation. It can be debated whether that the efficiency of personalized services depends on enabling users' choice and control, or instead on capacitating users' collaboration and response. Several scholars share the opinion that users

have to engage personally in order to experience better outcomes, and ways to discover and satisfy unmet needs include activating people's potentialities by co-planning and co-production [7, 56]. The criticisms towards the diffusion of direct payment as welfare solution [13, 20]



Table 2
Continued

Local health unit	Objectives	Governance structure	PTRI (Italian acronym for Personal therapeutic rehabilitation plan)	Professionals involved	Case manager	Agents	Financial tools
Piacenza	Taking care of the patient: not only health needs but also relational and communicative aspects of the treatment project	PDTAs (Italian acronym for Integrated Care Pathways). The Local Unit defined 9 PDTAs depending on condition, i.e: Fragile people Management Committee Director of Social and Health Local Unit, Director of Mental Health/Dependence Unit, Transition Psychiatry, District Directors, Director of District Plan Office Operative territorial groups Mental health professionals: social workers, psychiatrists, educators, professionals of the Mental Health Unit and of the Dependence Unit, social workers of the Municipality Conductor group Mental Health/Dependence Unit and social services of Municipality co-conduct personal plan	Biography of the patient Definition of: objectives, professionals, other informal operators and funds Electronic Tools Unified Electronic archive of PTRI. EFESO Programme. From 2020 personal dossier (Regional) and Social Folder	Fragile people PDTA Transition Psychiatry Social Service of the Municipality, users, family, professionals of the voluntary sector in collaboration with the Social Service of the Municipality	PDTA fragile people: case manager for mental health sector and for social service of the Municipality In particular instances, psychiatric counselling is provided	Local Health Unit, Social Service of the Municipality, agreement with voluntary sector	Fragile people PDTA Human resources of the Mental Health Unit and of the Municipality social services. Dedicated fund (Zone Plans, approximately € 9000/year). In some cases of psychiatric comorbidity, the Health Budget can be used
Caserta	De-institutionalisation: household placed in civilian homes (without health personnel, with social and health workers 24-hour coverage, and with case-specific staff members at the Health Mental Unit	Social-health coordination with administrative delegation to the Local Health Units Local social and health offices (single point of access) Local Integrated Evaluation Units: evaluation, planning Assessment tools VADO: for skills and goals; HONOS: for efficacy evaluation; ABC: for user satisfaction evaluation	PTRI is built on three objectives: •home/social habitat •training/work •affection/socializing	•The user and his or her family members •The Local Health Unit, through the services directly involved (Mental Health Unit, etc.) •The Municipality, through its social services •The private co-producers subjects (non-profit but also private profit organisations)	A psychologist with a coordination function.	Co-production public/private. Social and business agents chosen with regional public call for tender.	Local Health Unit: conversion of performance and redundant costs Municipalities: part of the resources of 328/2000 Law

suggest that enabling users and enhancing their abilities to self-manage their health and social status would produce better outcomes as compared with initiatives that focus only on patients' freedom of choice. The latter, indeed, can include simply being involved in selecting the preferred health treatment to meet one's own health-related needs, with the risk to develop consumer rights instead of citizen rights [29]. On the contrary, co-planning or co-producing services with users implies promote a full engagement of several agents, i.e., the users themselves and the public and private allies involved in building the personal plan at the local level [51, 58-60].

The studies that directly investigated the outcomes of increased choice found that choice is most beneficial when it enables enhanced-care relations. Gill *et al.* [61],

for example, reported that older people emphasised the importance of individualised services that encouraged front-line service providers to develop personalised relationships with them. In this example, "choice" becomes a mechanism for enhancing care relations, and the significance extends beyond simply choosing how to spend the money. Similarly, it has been reported that for people with mental health difficulties a key factor in enabling personal budgets to support empowerment and recovery is the quality and continuity of the professional relationship, a finding that raises particular implications for the organisation of mental health social work and the organisational cultures within which this is situated [62]. However, both self-direct and personal health budget have been reported to result in positive outcomes. A report of the Commonwealth fund de-

scribed that in the USA (in particular Florida and Texas programs) the users with severe mental illness had a positive shift toward prevention and early intervention, associated with improved outcomes, including more days in the community, higher scores on the Global Assessment of Functioning Scale, and greater percentage of participants in paid employment and training as compared with inpatient settings [23]. In 2013, the In-Control UK Agency reported a second phase survey on more than 2000 personal health budget holders [63]. The findings suggested that the personal health budget had a positive impact on independent living, the service access, and the control on one's own life. In addition, a large majority of personal health budget holders reported that their views were "very much" or "mostly included in their support plan" (older people 85%; people with learning disabilities 85%; people with mental health problems 81%; and people with physical disabilities 87%), with no differences across social care need groups, demonstrating a change towards a more participative welfare.

The introduction of greater choice, however, raises many concerns: the clarity on the available services, the information asymmetry between users and professionals also referred to the professionals' feelings about taking into account patients' preferences, the service quality actually chosen, and the meaningfulness of users' choice. Several scholars argued that the introduction of personal budget, especially when it is self-managed by direct payment, should pay attention to the balancing between taking risk and empowerment. In fact, in the personalisation model, increased choice comes with increased legal responsibilities and administrative tasks that many people and their supports find burdensome [26]. Furthermore, as in the case of mental health practitioners, people with enduring mental health problems [64] and people with dementia [65] are usually seen as incapable of managing personal budgets, and thus as subject to risk of financial abuse. However, a recent study by the UK National Institute Health Research Council evidenced that such concerns might be overstated [66]

Key factors for the success of personal budget within the Italian context

In order to properly support people to re-establish a fulfilled life, the administrative "silos" imposed by government funding and bureaucratic processes should be forced to pursue improvement in outcomes. Overall, greater emphasis should be placed on personal outcomes such as housing, friends, social networks, education, and employment alongside clinical care and treatment. The integrated care should involve the formation of multidisciplinary teams, such as multidisciplinary ambulatory outpatient care; cross-professional care; home rehabilitation; greater involvement of the community; improving family and community-based care; applying a community-based mental health model; training community-orientated primary care [3]. The challenge is getting agencies to work together across the divide, and also to involve the non-profit voluntary sector (called "Terzo Settore", i.e., Third Sector, in Italy), which comprises bodies that rely for

funding on charitable donations [8]. However, it is crucial to reflect on the most appropriate way of delivering personalised and integrated care. Indeed, it appears of paramount importance to modulate the ways to organise integrated care respecting the benefits of enhanced choice and involvement for people, without the added responsibilities of fully managing budgets. Personalisation should vary in proportion to the degree to which the person's involvement, knowledge, or leadership adds value to the quality of healthcare decisions and the outcomes achieved. This will require greater coordination across public services, as well as greater flexibility in the way health systems and social care resources are managed. Likewise, both universal services and community resources that promote inclusion and social connection should be 'patrolled' when services are offered, to avoid segregated settings [67, 7]. Finally, in order to design personalisation schemes that ensure health equity and outcome improvement, it appears necessary to take into proper account the existing structural social inequalities in the design of policy delivery systems [26]. Some parents and carers reported that they would need convincing evidence that the level of funding of personalisation scheme would be equivalent to what is already available. Some parents were also concerned that personalised demand for services may result in high demand for some services and a consequent reduction in those services that were "less popular", which may be particularly relevant where resources are already scarce, as is the case with rehabilitation therapies [14, 68]. To address the risk management of personalisation, some types of preventive practices have been suggested: first, exploring the protective value of increased choice; and second, developing risk assessment and risk management techniques to detect abuse or make it more difficult to occur [66]. Especially in the case of self-managed supports, users' preferences can conflict with workers' preferences; in this case, seconding users' choice alone disregards the labour rights and economic issues of carers. However, a more balanced approach that includes preferences of both of clients and workers may result in tensions [10]. Working conditions such as precariousness, invisibility, lack of "back up" workers for sick days, split shifts, and unpaid transportation to rural locales, and so on, should be faced and policy should offer solutions as well as standardise care worker credentials and education [69]. In this framework, training the professionals involved is a central issue when implementing personalised social care services [70].

In the previous section, we described the main welfare policies in the field of integrated care and personal health budget that were introduced in the last few decades in Italy. As compared with the international picture, the piece of legislation produced in Italy on this topic appears in agreement with the principles of person-centred care, community welfare, and 'more choice and control' for the users. Specifically, the regulation of social health integration shares, across regions, a similar overall formulation of the welfare system as well as a convergent definition of the strategic 'pillars' of the regional welfare scheme. Access, assessment, planning,



and monitoring are the steps of the path governing the individual care, and they may represent the solutions for the interconnectivity between social and health functions and territorial resources within the local environment, which is the place of implementation of the individual path. Prandini [10], in agreement with others scholars [18, 29, 46], argues that personalisation will be attained if developed within an appropriate context, including new type of professionals, users' led associations, and a new governance's architecture. If the public role is to shape freedom and control, help people to exercise choice in a collectively responsible way and, consequently, to participate in creating public goods, then it would be necessary to offer listening, supporting in decision-making processes, flexibility, balancing between support and self-management, and monitoring responsibility [19]. Unfortunately, in Italy few data are available concerning the impact of the recent welfare innovations. Prandini and Orlandini [56] reported a case study focused on the Sardinian disability policy. They showed how social policy's morphogenetic cycles affected the governance of personalized disability plans, and they highlighted the consequences of policy implementation. Some relevant findings emerged: i) users' pressure played a vital role in the switch from standard to personalised welfare strategy; ii) additional funding have to be paralleled with target professionals' training and introduction of new professionals; iii) the implementation could be enlarged (i.e. addressing more than one group of needs) only if the welfare system is resized to face the increased demand for plan design and implementation. In addition, the Sardinian case study shows that co-design and co-production modality survive if counselling provision capacity follows a rigorous programming. Otherwise, the public role comes down to a simple provider of monetary benefits, renouncing to play the generative role that the personalisation model is expected to play on welfare as social investment. A further case study recently reported concerns about the implementation of the personal health budget in a local health unit in the Campania region [51]. Finding from the first year of a pilot program that started on 2005 showed that the health budget methodology in Caserta led to significant cost savings, mostly associated with the reduction of institutionalized cases and the higher appropriateness of health care services. Besides, patients who qualified for the health budget methodology accessed more timely and suitable health treatment, and they showed an improvement on some items of the Health of the Nation Outcome Scales. In addition, families and patients reported a good level of satisfaction with the program.

CONCLUSION

Overall, the available data on the new welfare strategies that are geared more to social investment than to social protection corroborate the need to monitor national, regional, and local programs more systematically, and to undertake a comparative analysis of their governance strategies in relation to users and, hopefully, to selected outcome indicators. This is particularly true for Italy, where a national program aimed at ap-

plying and verifying the outcome at macro, meso, and individual level of a specific model of "personalisation" does not exist. First, we need to clarify differences and commonalities across the regional/local programs that promote a personal health budget scheme. An analysis involving at least two levels is desirable: i) analysis of regional legislation, population target, governance structure (nodes and agencies' role), professionals involved, funding strategy, and method of personal health planning; ii) analysis of individual outcomes in different groups with different needs. A further level that might carry substantial information would include the analysis of users', professionals', and stakeholders' perspective of the impact of the health budget implementation on their own life and organisations. Both strengths and limitations coming from these analyses can be of help to understand the 'determinant' factors that may allow to scale this welfare model at national or at least multi-regional level. It is worth noting that the available Italian models of personal health budgets represent, as well illustrated by Adinolfi *et al.* [51], an advanced model of personalisation involving high intensity of co-design, and in some case co-production, which offers a wide spectrum of welfare solutions. Unfortunately, there are only few experiences. Interestingly, in Italy there is an increasing, though preliminary, interest of the private [71, 72] and non-profit sectors [73] to create partnership with people with disability, suggesting that there is an action field to promote social investment and inclusion, which represents two markers of innovation to which the public sector should pay attention both at the local and national level.

Though decentralisation is one of the new modes of care [3], the central government plays an important role for guiding processes and locating investments and infrastructures suitable to guarantee quality, equity, and equal opportunities to people with long-term and chronic care needs. In Italy, policies addressed to harmonise welfare rules and opportunity, and to promote social investment and a stable monitoring framework, are urgently needed.

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There are no potential conflicts of interest or any financial or personal relationships with other people or organizations that could inappropriately bias conduct and findings of this study.

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