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Choice agendas in disability policy and practice: An analysis through the lenses of professional actors

The cases of England and Lombardy in comparison

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Chapter 5: Background of choice agendas in the two contexts of my study

As the title suggests, this chapter aims to reconstruct the background that informed the entrance and development of choice agendas in my two study contexts; as such, it sets the stage for the presentation of my research findings (Chapter 6). So far, we have seen what policies can be considered representative of choice agendas in the context of adult social care services for people with disabilities, in both England and Lombardy. However, the background against which these policies have developed in the two contexts is quite different: indeed, England and Lombardy represent different welfare traditions with different social protection regimes and distinct welfare actors involved in organising and delivering welfare services. It is thus particularly important to understand the terrain on which similar policies have developed out of these quite different welfare systems, and how so in order to locate my findings in their respective contexts and to also make sense of some of the references I will make while discussing them in the following chapters. For this reason, I present in the following order and regarding both England and Lombardy: 1) an overview of the welfare traditions in which choice agendas have developed; 2) an overview of the politics of choice agendas; 3) an overview of the available evidence regarding their impact; and, finally, 4) an overview of the specific field of adult social care services including, when available, data on disability.

Choice agendas: similar policies in different welfare traditions

England

England can be considered the ideal-typical example of the liberal welfare tradition characterised by low de-commodification, high incentives for market involvement in welfare related activities, and minimal public provision through means-tested assistance (Esping-Andersen, 1990). If we focus on the last fifty years of British politics, in fact, it is clear that these principles have informed the activity of different successive governments, from Margaret Thatcher's Conservative government of the late 70s and 80s to Blair's New Labour administration between 1997 and 2010 as well as the more recent Coalition and Conservative governments. To different degrees and in different ways, the liberal tradition has indeed influenced all these legislative frameworks.

It can be argued that the most radical interpretation of this liberal tradition was that of the Thatcher government between 1976 and 1990. With Margaret Thatcher, the Conservative party embraced the neo-liberal principles of free markets and individual freedom as the pillars that should drive any form of welfare intervention. Such principles are rooted in the work of Friedman (1962) and Hayek

(1990), both committed to theorising a model of welfare state centred around a competitive market economy in which state interference is minimal and human liberty – conceived in the negative sense as ‘liberty from’ constraints – is unleashed. Indeed, neo-liberals have blamed welfare states as formulated in the post-war period for having been coercive and having constrained – through policies inspired by the objective of ‘social justice’ – individuals’ free exercise of choice and, as such, human liberty. It was therefore on the basis of this anti-state rhetoric that Thatcherism made significant breaks with the British post-war approach to welfare.

Some have argued that the extent of the state ‘roll back’ actually carried out by the then-Conservative government was more limited than expressed by its original objective and that Thatcherism actually influenced British welfare policy mainly at the ideological level (Bochel, 2012). It is true that the British welfare state has somehow survived the fiercest attempts to transcend it, but so has the appeal to neo-liberal principles (or at least some of them). The election of New Labour in 1997 and the reforms passed throughout its thirteen years of administration attest to this reading. It was under New Labour, in fact, that the anti-public sector principles and policies of the previous Conservative government were framed within a more state-friendly discourse, and both new policy objectives and new policy discourses supported this operation. Blair’s New Labour thus constituted a deliberate attempt to reconcile neo-liberal ideals with those of traditional social democracy. The government’s declared aim was that of modernising the welfare state and the rationale for doing so was that the world had changed and so welfare states had to change too. Anthony Giddens (1973) has been the main theoretical influence behind the New Labour strategy and, because of the objectives outlined just above, this strategy was termed ‘The Third-Way’. In the end, however, far from actually introducing a ‘third’ or compromise-oriented path between traditional post-war conceptions of welfare and neo-liberal ones, the Third Way came under critique for having merged with neo-liberalism and legitimized some of the old neo-liberal mantras through new discourses and a new political language. One such discourse is that of ‘choice’. Choice agendas became popular precisely under New Labour and by virtue of their suiting both left- and right-wing political objectives. However, as we shall see, the application of choice agendas has given rise to individualistic and consumeristic interpretations of choice which more closely resemble liberal values than the egalitarian and social-justice objectives of social democracy. Choice agendas thus provide an example of how liberalism has always been at the heart of the British welfare state, albeit to varying degrees.

Lombardy

Over the past twenty years, Lombardy has developed its own specific and distinctive ‘welfare model’, taking to the extreme some typical features of the wider Italian welfare system, on the one

hand, and introducing new elements, on the other. In this section I will thus focus on providing a general overview of the typical Italian approach to welfare service provision from an historical and cultural point of view.

Italy has been categorised as both a ‘conservative-corporatist’ welfare regime and as part of the ‘Southern European’ family of welfare regimes. Indeed, Italy was the only Southern European country included in the original Esping-Andersen tripartition of welfare regimes: liberal, conservatist-corporatist and social democratic (Esping-Andersen, 1990). Together with Germany, Austria, the Netherlands and France, Italy was included in the category of ‘conservative-corporatist’ regimes. In such regimes, welfare provision has been typically associated with a mix of public insurance schemes based on individuals’ labour market position, rights closely linked to both status and socio-economic class, moderate levels of decommodification and, finally, the principle of ‘subsidiarity’: the idea that the state should intervene only when individuals, families and communities have exhausted their capacity to provide for themselves (*Ibidem*).

Developments in the Italian welfare system over the years, however, have led to the consolidation of social protection schemes quite distant from those of other conservative-corporatist welfare countries and more in line with those of other Southern European countries (Ferrera, 2012). The Italian welfare system displays three distinctive features in particular as compared to other conservative-corporatist systems. The first is the strong differentiation among the social protection schemes that different categories of workers are eligible to access. When compared to that of other European countries, this feature shows quite exceptional levels of juxtaposition between ‘covered’ (insiders) and ‘uncovered’ (outsiders) occupational categories in Italy, and it is the basis or cause of the country’s widespread black-market economy (*Ibidem*). The second feature typical of the Italian welfare system is instead related to its over-reliance on the role of families in providing a social safety net. Naldini (2002, 2004) uses the phrase ‘familiar and parental solidarity models’ to indicate a system that relies on intergenerational solidarity among family members, with relatives taking care of each other and meeting each other’s needs at different stages of their lives. The degree of defamilisation in Italy is indeed very low, and families perform a fundamental role in ensuring care and support for the most fragile members of their communities (Ferrera, 1996; Pavolini & Raitano, 2015). Finally, the third and last feature typical of the Italian welfare system regards the role played by civil society organisations and communities in delivering welfare services. Like families, communities are also expected to take care of themselves and the significant role played by the third sector in Italy reflects these expectations. Third sector organisations – with Catholic organisations at the forefront – have historically provided for many of the needs of their local communities, often without state financial support. Muehlebach (2012), for instance, stresses that, alongside the unwaged labour of families in providing care for their members, Italy has historically

also relied on the unwaged labor of volunteers in providing care for their communities. One quarter of the not-for-profit organisation workforce in Italy is actually made up of unpaid volunteers (*Ibidem*). Moreover, this feature of the Italian welfare system is strengthened by the high degree of localisation characterising the country's welfare system. Indeed, the fact that Italian regions are granted significant autonomy in managing social policy combined with the historically key role of civil society organisations involved in different sorts of welfare activities has favoured the development of many different 'local welfare' systems across the country (Bifulco, 2015). The outcome of this tendency, however, is that the Italian state has historically and chronically disregarded the need to ensure universal, guaranteed rights to basic levels of care for all those who need it. Despite legislative attempts to overcome this situation, such rights continue to not be respected.

It is therefore in relation to these historical and cultural trends that we need to consider both developments in a distinctive 'Lombardian model' of welfare provision and the evolution of 'choice agendas' within this model. Indeed, the convergence of the above-listed features distinctive to the Italian system has also shaped the Lombardian approach to public service provision. At the same time, however, Lombardy has drawn on the typically Italian principle of subsidiarity through family and community self-organisation but framed this principle within a market-oriented approach more typical of liberal regimes. The outcome has been the development of a welfare model in which the roles played by markets, families and communities are amalgamated and reciprocally strengthen each other. As I will show in the following section, 'freedom of choice' is one of the principles that has facilitated this amalgamation.

Beyond policy: the politics of choice agendas⁵

England

The institutionalisation of choice agendas in England took place under the New Labour government between 1997 and 2010 to then be supported by both the Coalition Government and, subsequently, the Conservative Government. Indeed, New Labour proved an enthusiast supporter of the idea of trusting in quasi-markets and the "invisible hand of choice and competition" (Le Grand, 2009), and this paved the way for daring policy changes in both the health and social care sectors. In particular,

⁵ The content of this and next section also draws on previous articles I have published, those already referenced in Chapter 4 (Pozzoli, 2018a, 2018b, 2019). Again, I will use relevant sections from these contributions in this chapter and supplement them with equally relevant new materials that relate to the specific topic of this research.

the enthusiasm with which New Labour pushed choice agendas in social care through ‘personalisation’ and its toolkit made up of DP and PB can be considered quite exceptional when compared to the more prudent stance of the previous Conservative government, the one that passed the Community Care (Direct Payments) Act in 1996 (Zarb et al., 1994). The restrictions originally introduced for DP as well as the demand for significant empirical evidence as a condition for their eventual expansion ended up being substituted by an idealistic determination to promote these tools (Beresford, 2014; Glasby & Littlechild, 2016). The shift has been drastic, as attested to by the monetary side of government support for DP and PB. In 2003, the Department of Health made available a £9 million Direct Payments Development Fund for setting up information and support services to expand DP provision while in 2008 – without even waiting for the findings of the Individualised Budgets pilot evaluation commissioned by the same department – the government invested over £500 million in taking personalisation and PB forward (*Ibidem*). The outcome of this swift investment was that, in less than twenty years, social care in England underwent what some have defined as its biggest change since the institution of the NHS in 1948. The main feature of this change has lain in the legislative endorsement of the right to PB as a due and guaranteed right, hence – in the eyes of policy makers and legislators – the purest possible form of personalisation (ADASS, 2017).

What is important to note, however, is that – as stressed by both Beresford (2014) and Carr (2010) – it was actually a group of actors from either governmental or third sector organisations who pushed this drive to support personalisation through PB, rather than disabled people themselves and their movements. *In Control*, *Demos* and the *National Institute for Mental Health in England (NIMHE)* are the organisations which have laid the groundwork for what then became the government’s personalisation agenda. For instance, *Demos’ report Personalisation through participation: a new script for public services* (Leadbeater, 2004) is considered to have influenced New Labour policy to a great extent, also in the field of adult social care (Carr, 2010; Gardner, 2011; Needham, 2011b); the same is true of *Making it Personal* (Leadbeater et al., 2008). Both documents emphasise an idea of personalisation underpinned by the concept of self-organisation – in the sense of users becoming consumers, commissioners and co-designers of services – and by the instrument of self-directed-support as a means of achieving such objectives. Leadbeater and his colleagues’ ideas made their way into government policy with *Putting people First* (HM Government, 2007) and, despite the critiques they came under in the following years, they still today represent the core of adult social care services in England. It is therefore the proposals of charities, think tanks and consultancy organisations that the government pushed through both legislative and monetary support and under the name of ‘personalisation’.

Choice agendas have their critics and opponents, and these include disabled people, disability activists and disabled people's organisations. Many of these critics are currently assembled around a network called the Social Work Action Network (SWAN) that continues to campaign for a different conception of personalisation, one distinct from the vision enshrined in government policy and based instead on emancipatory politics and radical social work principles (Ferguson, 2001; Ferguson & Woodward, 2009; Lavalette, 2011). However, this network cannot be compared – in terms of either practical influence or its ideological benchmarks – to the independent living movement or disabled people's movement active in England before the turn of the century. Its ability to gather supporters and influence policy is weaker, and both emancipatory and radical social work practice seem to have lost their momentum. Indeed, two of the most notable wins disabled people's campaigns had made in the name of 'choice and control' are currently being dismantled. One is the Independent Living Fund (ILF), a fund intended to support disabled people with high support needs to live in the community rather than in residential care. The fund has been closed and the responsibility for financing independent living transferred to local authorities, in a time of striking financial austerity. The other regards Disabled People's Organisations (DPO), once numerous across the country but today shrinking in scope. Due to a lack of adequate funding, many DPO have closed in recent years (Richardson, 2020), and this development cannot but undermine disabled people's representation and voice in regards to policy and the services they rely on.

Lombardy

Let us now look at the Lombardian case. The institutionalisation of choice agendas in Lombardy took place under the direction of successive Lombardian centre-right wing governments, especially, two of Formigoni's administrations between 2000 and 2010. Strong ideological drivers informed the development of choice agendas in Lombardy, with 'free choice' representing both a value in itself and a powerful tool considered capable of improving the quality of welfare service provision. Indeed, 'free choice' constitutes the core idea around which the region has merged the principle of subsidiarity typical of the Italian welfare system together with the principle of market-oriented reforms, thereby generating the so-called Lombardian model of welfare: "*il modello Lombardo*" (Carabelli & Facchini, 2013). In this model, 'free choice' is seen as fitting with both the valorisation of the role of families and communities as active actors of their own welfare and that of markets as welfare service providers. In fact, the condemnation and denigration of the state's role in organising welfare services in Lombardy has been closely tied to the valorisation of both families and markets (Bifulco, 2015).

Unlike England, therefore, in Lombardy it is not only market and quasi-market principles that have influenced choice agendas at the political level. Other ideological influences have been at play as

well, especially certain principles deriving from currents of Catholicism (Marotta, 2010) such as the Catholic Communion and Liberation (CL) movement (*Comunione e Liberazione, CL*) founded in the 1950s by Don Giussani. For instance, Roberto Formigoni – the governor of Lombardy at the moment when choice agendas were introduced into public policy – belonged to the CL movement and often acted, informally, as its political spokesperson⁶. In the view of the CL movement, the ultimate aim of public policy is to enable civil society organisations to respond to the needs of their communities and to do so as autonomously as possible. The CL considers the public sector an intrusive and inefficient actor of policy-making and a barrier to the expression of civil society’s creative potential. This is why CL would like to see the state step aside in the name of welfare societies, and these principles have underpinned the development of Lombardian choice agendas starting from the late ‘90s.

The first field to be affected by choice agendas in Lombardy was health care services, as the region built a system totally centred on the role of markets in organising and delivering health care services. This move represented an exception in Italy in that other regions’ health care systems are organised around different principles, such as that of co-production between public and private actors or that of public authorities taking the primary role (Bifulco, 2015; Neri, 2009). Starting in the early 2000s, choice agendas expanded from health care services into social care. The result, as noted earlier, is that Lombardy is currently the only Italian region to have implemented a reform of its social care system that is likewise wholly centred around market mechanisms and quasi-markets reforms (Bifulco, 2015; Neri, 2006).

Free choice through marketisation, the valorisation of families and communities, and the denigration of the role of the public actor are thus the ideological drivers through which choice agendas have developed in Lombardy over the course of the last twenty years, despite warnings from both academics and civil society organisations regarding the limits and risks of these ideological positions. For instance, when quasi-markets and voucher-style reforms were first implemented in the region of Lombardy, scholars pointed out that these reforms had the potential to create information asymmetries among users and between users and providers, perverse market incentives and inequality of access, treatment and outcomes for service users (Montaleone, 2005; Vitale & Bifulco, 2005). Bifulco (2015) also stressed that, when market actors are involved, communities’ roles in organising and delivering welfare services risk being reduced to market objectives and interests. Despite such warnings, however, the Lombardy region continued to invest in the ‘Lombardian model’ through successive legislation. Even when it proved necessary to

⁶ In 2012, Roberto Formigoni resigned as governor of Lombardy following scandals and charges of bribery and corruption which also involved his role of spokesperson for CL. In 2016, following four years of investigation, he was sentenced to six years in prison for bribery and corruption.

consider and implement changes to the model – for instance by increasing the role played by public administrations in organising and regulating welfare services – supporters of the ideological drivers of the Lombardian models have continued to support these principles.

Some have argued that the Lombardian model exerts more influence in principle than in practice (Gori, 210) while, more recently, Cataldi and Cappellato have observed that Italian welfare reforms are increasingly dominated by new welfare discourses centred on concepts such as ‘civil welfare’, ‘community welfare’, ‘welfare society’ and ‘generative welfare’ (Cataldi & Cappellato, 2020). What is interesting to highlight is that the specific form these new welfare discourses take in the region of Lombardy is referred to as ‘second welfare’ (*secondo welfare*). This term first appeared in 2010 to denote the specific features of a welfare system based on integrating ‘first’ or more typical public welfare actors and ‘second’ or less typical private-sector ones, from families and individuals to companies, banks and foundations and a wide range of different third-sector actors (Ferrera, 2010; Ferrera & Maino, 2013; Maino, 2015). ‘Second welfare’ is not a product of regional policy-making; the main actors behind it are companies and civil society organisations, including big banking foundations. Nevertheless, I believe ‘second welfare’ to provide an observable example of the fact that the principles informing social policy in Lombardy have not really changed; at most, they have been applied in new ways. Individuals, their families, communities and privately arranged forms of welfare provision continue to represent the core of the Lombardian model of welfare.

What does the evidence say?

England

As suggested by the above section, the debate around personalisation and self-directed-support in England is still active and heated, and personalisation can still be said to have major supporters but also fierce critics. Again, the former include government and government-funded organisations or partners such as *SCIE (Social Care Institute for Excellence)*, *TLAP (Think Local Act Personal)* and *In Control*. The latter are activists and vocal defenders of the principles of the independent living movement – such as the Social Work Action Network seen above – who see their claims as having been co-opted by government politics. In 2014, Needham and Glasby referred to personalisation as either “the best thing since sliced bread or the end of the welfare state as we know it” (Needham & Glasby, 2014, p. 5), and pointed to the difficulties involved in finding common ground between these two positions. Today’s situation is no different, and evidence-based research – despite its intentions – has not proven very helpful in clarifying matters.

On the one hand, DP and PB are found to have improved the experiences of community care users and to have brought about positive transformations in social care services. Moreover, such aspects are highlighted mainly by evidence-based research drawing on either the *IBSEN Report* (Glendinning et al., 2008) – the most recent evaluative study of the individual budgets pilot commissioned by the government – and its dataset (Davey, 2018), or the so-called *Personal Budgets Outcomes and Evaluation Toolkit (POET)* studies: reports published on the basis of surveys developed by *In Control* together with Lancaster University and designed to measure the experiences of people receiving PB across adult social care and health care (Hatton & Waters, 2013; Hatton & Waters, 2011; Waters & Hatton, 2014).

On the other hand, however, this kind of research has been criticized for having instrumentally and ideologically stressed the positives of ‘personalisation through SDS’ over the negatives. For instance, Beresford and Slasberg have highlighted that these evidence-based studies have focused on ‘what works’ as opposed to ‘what doesn’t work’ in regards to PB, sometimes using questionable methodological approaches and usually by wielding the appeal of powerful personal stories (Beresford, 2014; Slasberg et al., 2013, 2014; Slasberg & Beresford, 2016, 2017). Richardson has instead noted that this same evidence-based literature has also restricted the scope of personalisation to DP and PB tools, explaining any dissatisfaction on the part of community care users as caused by procedural or implementation difficulties rather than questioning the model of SDS in itself (Richardson, 2020). Other authors have questioned the central assumption on which PB are built, assumptions which the above-mentioned evidence-based literature has not interrogated: the idea that comprehending and controlling a pot of money allows care service users to exercise choice and control (Slasberg et al., 2015). Not only is this seen as a very limited notion of choice and control – one which undermines social and civic rights in favour of market-based rights (Daly, 2012) – but critics have also argued that this notion has subverted the original emancipatory values of disability activism, helping to translate a neo-liberal and individualistic ideology around choice into public services (Ferguson, 2012; A. Oliver & Evans, 2005).

There are also studies conducted over the past ten years that have questioned the extent of the benefits of DP and PB by also employing evidence-based approaches. Some, for instance, have highlighted the unequal distribution of the benefits of SDS across different users’ groups (Fernández et al., 2007; Woolham et al., 2015). Others, instead, have shown that the take-up of DP and PB has always varied a great deal across local authorities in England and, even now that PB are mandatory across all local authorities, there continue to be significant differences across the country in terms of how many budgets are council-managed as opposed to directly-managed (NAO, 2016). More recent research (Bottery & Ward, 2021) has also shown that, if we take the number of DP as an index of personalised care, there seems to be less personalisation across England now than

in the past few years. The number of people using DP has indeed fallen this year, for the third consecutive year (*Ibidem*).

Austerity has been blamed by many of these outcome. Budget cuts combined with greater demand and reduced supply in England's social care sector has indeed drastically affected service delivery since 2010. This effect is so great, in fact, that even authors who strongly advocated for personalisation have come to question if the recent financial climate might possibly represent the most dangerous risk ever faced by personalisation and its toolkit (Duffy, 2012; Glasby & Littlechild, 2016).

Whether personalisation and its toolkit are actually facing their final crisis is debateable. All users of social care services today receive a PB, and these are rapidly spreading into health and education services as well. Needham (2011a; 2011b) has described personalisation as a dominant narrative in the context of public services in England, one built around certain compelling "story lines" which make any form of questioning or critique difficult: personalisation works, it saves money, it recognises people as experts of their own lives, it reflects how people live rather than how services work. In this sense, personalisation is seen as the solution to the failures of traditional welfare states which, because of their top-down, standardised and authoritarian practices, have been targeted by accusations from many fronts that they encourage welfare dependency and institutionalisation. Even in the context of the aftermaths of the Covid-19 pandemic, the narrative of personalisation seems to continue flourishing. A recent article published in *CommunityCare* (Mithran, 2021) points out that *Think Local Act Personal* have showcased positive stories of people using DP during the pandemic, suggesting that, in such cases, councils have allowed less prescriptive approaches and more tailored-made support solutions. Given that the narrative of personalisation still receives strong support, therefore, it is reasonable to think that this narrative is not destined to be short-lived and that, on the contrary, its story lines will continue to underpin social care, at least for some time to come.

Lombardy

In Lombardy, the region's support for evidence-based policy making in regards to reforms affecting the health and social care sector throughout the past twenty years has been weak if not wholly absent. In particular, as Gori (2005) maintains in regards to what I am calling choice agendas, freedom of choice and trust in quasi-markets animated the direction of the Lombardian centre-right wing government during and after its first legislative period regardless of a lack of evidence or analysis regarding required reforms. And the situation has not changed since. The evidence regarding welfare regional policy in Lombardy that is available is not commissioned by the government, but rather produced independently by a group of experts and researchers gathered

around *LombardiaSociale.it*, a project aimed at analysing and researching Lombardian welfare policy and policy-making. It is the experts and researchers of *LombardiaSociale* who have produced the most comprehensive analyses of the Lombardian model of welfare so far. Their contributions are collected in three main books – *Politiche sociali di centro-destra: La riforma del welfare lombardo* (Gori, 2005); *Come cambia il welfare Lombardo. Una valutazione delle politiche regionali* (Gori, 2010); and *Il welfare delle riforme? Le politiche lombarde tra norme ed attuazione* (Gori, 2018), and presented on the website *LombardiaSociale.it*. These contributions have produced a large body of evidence and research regarding the Lombardian model of welfare over the last ten to fifteen years. However, I would argue that, even when such evidence and research started to emerge, it was not taken into significant account at the political and policy levels.

For instance, regarding the impact of Lombardian reforms on support and services for disabled people, a key point that has been stressed by the *LombardiaSociale.it* working group focusing on disability policy is that, for people with disabilities, freedom of choice has translated into a system which incentivises service users and providers to liaise directly, without intermediation on the part of social services. This outcome has not necessarily been deemed positive by disabled people and their families, however; on the contrary, these direct users have instead experienced a lack of support and guidance around planning and difficulties both in sourcing the available offering and in liaising with providers (Abet et al., 2010), possibly because of information asymmetries. No significant change in direction was made following the emergence of this evidence, however. Another aspect highlighted by the same *LombardiaSociale* working group is that, as a result of the voucherisation and accreditation system set up by the region, the Lombardian service offering did actually increase in terms of capacity, extending to reach more people who had previously been excluded from services. However, this enlargement has gone hand in hand with the standardisation of the regional offering into rather inflexible services, a situation which has led to the standardisation of the pathways people with disabilities are able to undertake and which, over time, has also caused the saturation of available services. For instance, it was common for adults with a learning disability to leave school between the ages of 16 and 25 and enter day services which they would usually not leave until the age of 65, when they entered the ‘older age’ phase of their lives and were thus transferred into to some elderly people’s service (*Ibidem*). Nowadays this tendency is a bit less common; however, this shift is not because ‘pathways’ became more flexible but because services reached full capacity. In this case as well, however, these outcomes did not lead to any real changes in direction at the level of Lombardian policy-making.

There is thus a body of research focused on specifically analysing how vouchers have been used to purchase home care services by both disabled people and the elderly. This literature presents findings similar to those discussed just above. For instance, users initially appreciated freedom of

choice in terms of selecting home care providers because the introduction of the new system allowed for an expansion of service coverage in the sense of both more services and more hours. More resources were indeed dedicated to the introduction of vouchers and *buoni* to purchase domiciliary care in the early 2000. On its own, however, users found freedom of choice to be quite limited and, in many cases, even perceived it as a burden (Giunco, 2010; Pasquinelli, 2006; Tidoli & Marotta, 2010). Moreover, the capacity of Lombardian home care services to respond to the needs of all of today's potential users has shrunk dramatically, if we consider that only very few people across the region are currently covered by domiciliary services (NNA, 2017; Pasquinelli, 2020). Finally, over the years, choice has remained confined mainly to selecting among home care providers rather than enabling more innovative opportunities for planning, another element perceived as limiting disabled people's chances of actually exercising control over their lives (Cicoletti et al., 2010).

One last noteworthy point the working group of *LombardiaSociale* has made about the Lombardian social welfare system regards its inability to overcome a limit typical of the wider Italian welfare system: its bias towards unconditional cash-for-care. Italy is indeed the European country that invests the lowest percentage of resources in services and the highest in monetary transfers (that is, unconditional cash-for-care), and scholars have stressed the need to start diverting investments into services (Gori, 2014). Moreover, many scholars are now calling for a reform of the *Indennità di Accompagnamento* – a state-provided monetary benefit for non-self-sufficient individuals – designed to tailor resources to needs and contexts and introduce incentives to link the allocation of the benefit to the service sector (Pasquinelli, 2015; Ranci et al., 2017). This reform is seen as necessary because unconditional cash-for-care has been recognised as impeding both the equality and adequacy of treatment, reinforcing the typical Italian reliance on families and unqualified care workers and failing to address pressing labour issues such as workers without contracts, training, or rights (Ranci et al., 2017). The Lombardian model of welfare service provision has thus been criticized precisely in these terms: for having further incentivized – in the name of free choice and through the promotion of *buoni* and other forms of cash-for-care with a very low degree of conditionality – welfare services' historical reliance on the informal care provided by families and unqualified care workers.

Some timid signals of change started to emerge around approximately 2013. Indeed, observers have noted changes at the level of regional guidelines and objectives for policy-making: there have been some small shifts – amidst the values of freedom of choice and the mechanisms of 'voucherisation' – towards stressing the importance of also investing in better support and guidance for people, better integration among services, and more resources so as to reach the still-excessive number of people not receiving any support or services (Ghetti, 2018). As I mentioned above, FNA funds for

people with very severe or severe disabilities, the funds attached to the *After Us* law, and the *autonomy vouchers* represent a move in this direction. So does the piloting of combined budgets (*Budget di Salute, BdS*) in some municipalities in the province of Milan. It is too early to evaluate the impact of these new initiatives, and indeed only a small body of grey literature is available on them. What such literature does seem to suggest, however, is that the region's declared intentions have not actually translated into a drastic system-change, at least not yet. Free choice through vouchers and unconditional cash-transfers continue to inform Lombardian policy-making.

Choice agendas and adult social care: the magnitude of the impact

With this last section I will provide some data useful for better understanding what services have been affected by choice agendas in both England and Lombardy, and to what degree. The way this information is presented reflects the nature of the available data. In England, for instance, a rich body of data and analysis is available regarding the way adult social care responds to the different needs of disabled people; in Lombardy, instead, the lack of official institutional data makes it extremely difficult to conduct a comprehensive analysis of the adult social care sector with a specific focus on disability.

England

Choice agendas in England affect all people with disabilities who receive support from their local authority adult social care services and because of their care needs. A recent analysis from the King's Fund (Bottery & Ward, 2021) shows that 1.93 million adults sought social care support in 2019/2020 and that the demand for social care has consistently increased since 2015/16, especially among working-age adults. The extent to which such demand has been met, however, has decreased over the same period, reaching just over 1 million people in 2019/20. In fact, since 2015/16 fewer people have been receiving care services from their local authorities. Austerity has been a key driver of this reduction. Local authorities' spending power across England has fallen significantly as government funding for local authorities dropped by 55% between 2010 and 2020 (*Ibidem*). Throughout this period, adult social care continued to represent the largest area of spending (43%) for local authorities (NAO, 2018) and authorities have safeguarded social care budgets more than those of other services. As a result, in 2019/20 they managed as such to return to the expenditure levels of 2010/11. Nevertheless, demand is higher today and the costs of providers' services have increased, with the result that fewer users in need of care are currently accessing adult social care as compared to the past (Bottery & Ward, 2021).

Moreover, not all people receive social care support for free. Social care in England is means-tested and, if a person has more than £23,250 in savings, they will be required to pay for the full cost of their care. If their savings are instead between £14,250 and £23,250, they will be required to cover a portion of the cost of their care. Since 2014/15, local authorities have raised more money from charges on services and this means that, while local authorities managed to raise their social care expenditure levels, fewer people received publicly funded care (*Ibidem*). It is difficult to estimate the number of self-funders (people who pay for their own care) in England. In fact, this population includes both people who do not request adult social care support and people who do not qualify for it. However, estimates of the value of care for adults in 2016/17 suggest that self-funders' spending on adult social care comes to £10,9 billion while that of local authority comes to £20,4 billion (NAO, 2018). These estimates gain particular relevance when compared to those of informal care: nearly £100 billion per year (*Ibidem*). In fact, they suggest that most care in England is provided informally, either by families, friends or neighbours.

If we focus specifically on the numbers of personalised care, there are two main aspects we can identify based on available data. The first one regards the uptake of direct payments and personal budgets among people with long-term support needs who receive support in their own homes. Despite successive governments' large financial and rhetorical investment in promoting personalisation through DP and PB – and despite the fact that PB are now a guaranteed right in England – the percentage of people receiving DP remains particularly low especially among certain user groups, while the percentage of local authority-managed PB continues to be quite high. People with physical support needs are by far the largest group who receives home care support through DP, making up 50% of the cases. This percentage falls to 40% for people with learning disabilities, 20% for people with mental health support needs and 16% for people aged over 65. Specularly, 75% of older people, 53% of people with learning disabilities, 44% of people with physical disabilities and 33% of people with mental health needs receive a council-managed PB (NAO, 2018). What is interesting about these figures is that home care is the sector that has reported the greatest use of PB through DP. This is due mainly to the number of people with disabilities employing their own Personal Assistant (PA) through DP for home care support. Even in this sector, however, apart from people with physical disabilities who are thus more likely to employ their own Pas, relatively few people have come to receive PB through DP. Council-managed budgets (which really cannot be considered a tool for self-directed-support) instead dominate the provision of home care support, suggesting that choice agendas have been much less successful than originally auspicated.

The second and final aspect of the personalised care numbers I would like to highlight displays a similar tendency. The percentage of people using DP fell to its lowest level since 2015 in 2019/20,

following two years of constant reduction (Bottery & Ward, 2021). Various explanations have been provided for this trend, from the fact that DP support services vary from one local authority to the next, to the fact that people might not be interested in taking on the extra work and responsibility of managing their own support, to the fact that DP might actually not allow more choice, especially if there are not many options available from which to choose. However, there is currently a growing consensus that – beyond the employment of Personal Assistants – receiving PB through DP might just not be an appealing option (*Ibidem*).

Lombardy

Choice agendas have informed the organisation of the Lombardian model for delivering care and support to people with disabilities and, as such, they affect all disabled people who use care and support services in Lombardy. However, ‘measuring’ the extent of this influence in terms of either recipients or expenditures is quite difficult. For instance, we know that in 2017 the total spent on Lombardian welfare services was €1,905 million, with €1,712 million dedicated to the social-health care sector (*settore sociosanitario*) and €193 million to the social sector (*settore sociale*). However, both sectors are responsible for organising and delivering different services for people with disabilities, the elderly, children and young people, and it is very challenging to extrapolate data on all these different categories (Gori & Melzi, 2018).

There are three main reasons for this. The first has to do with the fact that available care and support services are managed by different regional departments, and rarely in collaboration. Various and non-communicating funds finance the Lombardian welfare system, from national to regional and European funds, and these funds are directed to and managed by either social services (municipalities) or social-health care services (local health authorities). For instance, if a person with a disability receives home care support and also attends a day service in Lombardy, their home care support is financed and administrated by their municipality while their day care is financed and administrated by their health authority, and none of these services necessarily know about the other one. The second reason therefore has to do with the absence of official data from the region regarding its budgets and how they are allocated. Although reconstructions have been attempted, these have proven feasible for the social-health sector but not for the social one (*Ibidem*). Last but not least, there is a lack of accurate estimates regarding the needs of the Lombardian population and this lack further complicates the scenario in question. As a matter of fact, funds are not allocated to different local health authorities across the region based on their respective population needs and, similarly, resources are not allocated to service providers based on estimates of who would make use of them. On the contrary, funds are allocated to local health authorities based on negotiation processes between the region and other relevant actors, and resources are allocated to service

providers based on their previous year's activity (and also regardless of the quality of service provided) (*Ibidem*). The way resources end up being allocated across the region is thus highly inconsistent, and the data regarding such allocations is extremely limited.

The scenario we can sketch based on the little data we do have is the following. There has been a slight increase in recent years in the overall amount spent on social and social-health care services in Lombardy, especially in the social care sector. In 2017, for instance, the extent of such increase was €179 million. Compared to the spending levels of the first years of choice agendas (2000 – 2010), however, this figure points to a quite static spending trend: the pace of the increase has been falling year after year. Furthermore, much of the documented increases in recent years are due mainly to the introduction of new funds to finance care and support services for people with disabilities, especially people with severe disabilities, at a national level (e.g.: *Non-Self-Sufficiency Fund* for severely or very severely disabled people, namely the *B1* and *B2* measures and *ProVI*, and funds linked to the *After Us* law for severely disabled people who have lost or are at risk of losing familiar support). And it is the availability of these new national resources that has more recently made it possible to reach many disabled people who had not previously been registered with services. Moreover, in regards to the social care sector, national but also European funds are increasingly contributing to enlarging regional budgets while specifically regional funds are actually decreasing, a point viewed with concern by experts and analysts in the sector (*Ibidem*).

What experts and analysts have shown, indeed, is that despite slight increases in overall regional budgets and the appearance of new extra-regional funds, the reach of the Lombardian welfare system remains highly insufficient. For instance, many people are still not registered with or are excluded from services, especially elderly people and people with disabilities whose needs are not considered very severe. Moreover, in the majority of cases the people reached by new national funds have received monetary transfers that partially cover the costs associated with their care but no in-kind care (Gori, 2018). In addition, home care services are extremely limited (Fosti & Noranicola, 2019), independent living opportunities have been reduced to a bare minimum and there are few opportunities for personalised care as an alternative to residential care (Merlo et al., 2018). To paraphrase Merlo, therefore, the overall portrait of this sector shows that most people with a disability in Italy are destined to remain in the care of their families as long as family members are able to provide such care, and when familiar support is no longer available, they are likely to enter a residential service (Merlo & Tarantino, 2018). Hardly a destiny, we could conclude, that allows disabled people to exercise real choice.