

## Introduction: disability rights and wrongs in Italy

David Forgacs<sup>a\*</sup> and Rachele Tardi<sup>b</sup>

<sup>a</sup>*Department of Italian Studies, New York University, New York, USA;* <sup>b</sup>*Light for the World, New York, USA*

This is the first issue of *Modern Italy* to focus on disability. We want to thank the general editors of the journal, Philip Cooke and John Foot, for having welcomed our proposal for it. The original nucleus was the panel ‘Disabilities’ at the conference ‘Language, Space and Otherness in Italy since 1860’, which David Forgacs organised at the British School at Rome on 24–25 June 2010. The decision to include a panel on that topic was influenced, in turn, by Rachele Tardi’s experience in 2009–2010 of managing a project in Ethiopia, funded by the Italian Foreign Ministry, for the NGO Comitato Collaborazione Medica, which worked with local partners on community-based rehabilitation (CBR) of people with disabilities. Our discussions of CBR at that time stimulated our interest in looking more closely at the contemporary situation of disability rights in Italy. Our main objective in editing this issue has been to offer readers a representative sample of writing both by Italian disability activists and researchers and by non-Italian scholars working on Italian disability issues. We deliberately sought a mix of academic writing and writing by people actively engaged in work for disability rights. Giampiero Griffo, who was the discussant at the conference panel and is one of the authors included here, was a willing mediator for other articles, and we would like to thank him for his support and help in making this issue happen. We also thank Franco Baldasso for his hard work assisting the editorial process, our peer reviewers for their invaluable input, and our translators, Bryan Brazeau, Kristin Szostek Chertoff, Brian DeGrazia and Stuart Oglethorpe. We should also like to thank Pier Vittorio Barbieri, Claudia Bertolè, Flavia Monceri and Antonio Pascale.

We have borrowed the title ‘Disability rights and wrongs’, with permission, from Tom Shakespeare (2006, 2013), who put us in contact with the authors of two further articles and whom we also thank. The phrase seems to us to capture a central contradiction of the Italian situation: on the one hand, some of the most advanced national disability legislation in the world, combined with a well-developed culture of advocacy and self-advocacy for the rights of at least some people with disabilities, rooted in Italy’s strong traditions of social protest and civil society activism; on the other, a weak welfare state and low public expenditure on disability by comparison with many other European Union member states, plus relatively low public visibility of certain groups of people with disabilities, for instance those with learning difficulties. The negative side of the situation has now become very serious. As we write, cuts to disability benefits and dwindling employment opportunities are threatening to push increasing numbers of Italian people with disabilities over the edge into poverty. Italy is not the only country in which this is happening, since cuts to social benefits have become a common economic austerity

---

\*Corresponding author: Email: [david.forgacs@nyu.edu](mailto:david.forgacs@nyu.edu)

measure across the EU, but people with disabilities in Italy were already in a more precarious position than in many other member states. In 2005, when average expenditure on disability benefits across the EU in 2005 was 2.1% of GDP, in Italy it was just 1.5% (Eurostat 2008, 4). In 2008 Italy was in 18th place among the 27 EU member states at that time in public expenditure in favour of persons with disabilities. The recent cuts, therefore, have hit people there particularly hard.

In order to help readers navigate through the issue we shall summarise here briefly some key aspects of the social and legal situation relating to people with disabilities in Italy over the past half-century and also say a few words about the articles themselves. In Italy, as in many other Western countries, attitudes towards disability and the entitlements of people with disabilities have changed markedly since the end of the 1960s. Until then, many children with physical or intellectual impairments were placed in residential institutions, managed either by provincial administrations or by the Catholic Church, in some of which, as emerged in a series of court cases during the 1960s, they were severely neglected or abused (Crainz 2003, 114–116).<sup>1</sup> The majority of children with disabilities had no access at that time to mainstream schools and most of those with intellectual disabilities were deemed ineducable. As for adults, those with physical or intellectual impairments, with the partial exception of war invalids (*mutilati di guerra*), had no entitlement either to paid employment or to state benefits or pensions towards maintenance. There were no official requirements to make buildings, transport systems or toilets accessible, no statutory housing benefits, no living allowances for people with disabilities, no means of entry into the regular labour market. Nevertheless, as Matteo Schianchi notes in his article in this issue, there were already a number of voluntary associations advocating in Italy for people with disabilities. A war invalids' association had existed since the end of the First World War and associations of people with sensory impairments had formed in the 1920s and '30s. However, it was only after the Second World War that they started to gain greater public visibility, notably through the series of *marce del dolore* (pain marches), including those organised in Rome in 1961, 1964 and 1968. Other associations were formed in the 1970s, organising petitions and lobbying parliament, for instance over access to employment (see also Schianchi 2012, 222–226).

By the mid-1970s movements and initiatives of people with disabilities were growing internationally. An important landmark was the creation in the USA of the first Center for Independent Living in 1972. These were years of change both in attitudes and in the law, and what happened in one country often influenced what happened in others. In Italy the changes were affected also by the political radicalisation linked to the social protests of the late 1960s. People with disabilities started to be seen as part of a larger set of the socially marginalised (*emarginati*), consisting of several partially overlapping groups of people, including those defined as having a mental illness, the elderly, the homeless, the long-term unemployed and former prisoners. The arguments of the 1970s for the human and civil rights of people with mental illness, and for the closure of long-stay psychiatric institutions (*manicomi*) are much better known internationally than those for the inclusion of persons with disabilities, not least because of the prominent public profile of Franco Basaglia and some of the other members of *Psichiatria Democratica*, but both sets of arguments developed at the same time and the legislative changes that accompanied them had a common ideological core. Indeed, it was their strongly rights-based character that differentiated them from the otherwise similar legislation that developed in that period in the UK.

We can illustrate this difference with a personal example. In 1982 David Forgacs's first daughter, Amy, was born in Brighton with Down's Syndrome. From when she was a few months old, Amy benefited from an early learning programme called the Portage Project and her mother

and David wanted her to attend mainstream schools rather than special schools. This option had just started to be available then in Britain thanks to the 1981 Education Act, based on the recommendations of the Warnock Report on Special Educational Needs (1978). This followed the integration measures then being enacted in the USA (Education for All Handicapped Children Act, 1975) and in France (Framework Law 534, 1975). In 1984 David learned that a similar law had been in force in Italy since 1977. Like the British law, it established the principle that all children with disabilities should be integrated into mainstream state schools (*scuole d'obbligo*) and should be assisted in class when necessary by a support teacher (*insegnante di sostegno*). However, whereas the Italian law made it a blanket obligation for schools to integrate all children, the UK law contained what was in effect a let-out clause, Article 2(3), permitting a local education authority (LEA) not to fulfil this duty when it was not 'compatible with the efficient education' of the other children in the same class or with 'the efficient use of resources'. The result was that different LEAs in Britain came to adopt different positions towards their obligations under the law. Some strongly supported integration; others were more cautious and argued that integration would harm other children's learning, or would require extra resources and be too expensive, and therefore they kept their special schools. Amy was fortunate because she lived in areas with supportive LEAs and head teachers and she went through her whole education in mainstream schools.

One might perhaps describe this as a contrast between British pragmatism and Italian radicalism and applaud the latter. There were, however, negative aspects to the experience in Italy too. Although formal integration in schools was nearly universal from the start, there were significant differences from one region to another in the amount of financial support made available to help it work in practice, for instance by providing ramps or stair lifts, accessible toilets, Braille textbooks and assistive devices. Moreover, there was a problem in many schools of negative or uncooperative attitudes, both among teachers, who were often unprepared to deal with children with disabilities, and among other pupils. It was all too easy for the child with a disability to become marginalised anew – to be either ignored or bullied – in a mainstream classroom and for the project of integration to fail. Overall, not enough thought was put into what it actually meant to involve children with disabilities both in and out of class. Teachers needed to receive special training, pupils needed guidance to understand that not all children were the same, support teachers needed to be freed up at times to work with the whole class rather than being permanently hitched to one 'special' child, who thereby became ghettoised. Radical ideas and policies, in other words, were not being matched by adequate solutions or support on the ground in the schools themselves. Above all, this was a project, to use a distinction that is made now, of integrated rather than inclusive education. Inclusive education means that the child is not just inserted into the mainstream curriculum but participates fully and equally with all other children in the whole life of the school. In other words, the learning environment has to change so that the child with disabilities is not seen as a problem, and that change has to be sustainable.

Such limitations in practical implementation have been a recurrent problem in Italy in many other aspects of provision for people with disabilities. One of these aspects is physical accessibility. The situation has been slowly improving over the years, including in historically inaccessible cities such as Venice, but in 1986, when the laws on access of people with disabilities to school and workplaces were already in force, Franco Piro and Lia Gheza Fabbri observed that in Italy one still saw relatively few wheelchair users outdoors, unlike in Scandinavia, Germany or the USA, because its shops, cinemas, theatres, pavements and public buildings were for the most part inaccessible and its beautiful churches were full of steps, 'as if

simple means did not exist to reduce these barriers, which are as much a matter of mental attitude as of urban physical structure' (Piro and Fabbri 1986, 10). Another aspect, which we have already mentioned, is inadequate public expenditure in favour of people with disabilities.

Yet it does not have to be like this. Despite its continuing public debt crisis and its high unemployment rate, Italy remains a rich Western country in which many of the existing barriers to social inclusion could be reduced or even eliminated if enough resources and political will were directed to this goal. The problem is that a mismatch remains between what the laws prescribe and what gets achieved, between the aggregate income of Italy's wealthier citizens and the amount its governments are prepared to commit to social spending, between the demands of disabled people's organisations (DPOs) and the responses of central or local government.

A key problem has been how to make the legislation that is already on the books effective for all people with disabilities. The 1977 law on integrated education has been just one of a series of laws introduced since the late 1960s. Two others, passed in 1968 (Law 482) and 1971 (Law 118), made provision, respectively, for access to work (Law 482 introduced the concept of compulsory quotas of people with disabilities whom employers were required to hire) and for accessible buildings, including schools. The issue of employment quotas has been controversial. They have been introduced in many countries, but they have rarely been successful, with Germany and some of the former Eastern bloc countries being possible exceptions. They can flout; they can be fulfilled in a tokenistic way; and they suggest that disabled people can only get jobs if they get special treatment. Anti-discrimination legislation is perceived to be a less stigmatised solution, although it too has only had a limited success in improving employment rates. In the early 1990s a framework law (*legge-quadro*) was passed (Law 104/1992), which sought, among other things, to improve the integration of children in schools through an individual learning plan (*piano educativo individualizzato* or PEI) and to get better coordination between schools, families, medical and social services. It also introduced new regulations on accessible buildings and access to transport and it made provisions for entry into employment of adults with disabilities through professional training schemes and revised work placement norms. The latter were further enhanced by Law 68/1999, 'Norme per il diritto al lavoro dei disabili' ('Norms on disabled people's right to work'), which introduced the concept of *collocamento mirato* (targeted work placement). This was based on a system of personalised assessments, designed to enable individuals with disabilities to be appropriately placed rather than randomly allocated to jobs for which they are not suitable or where the working environment is not suitably adapted for them. One of the limitations of this law is that it applies only to workplaces with more than 15 employees, whereas the vast majority of employers in Italy have fewer employees than that. Two of the articles in this issue – by Fabio Ferrucci and Fabio Corbisiero – deal with this legislation. Both examine the obstacles that exist in practice to an effective implementation of the norms on *collocamento mirato* and both stress the importance, in order for a real inclusion of people with disabilities to happen in workplaces, of understanding work as a full set of social and human interactions and not merely as the performance of one or more tasks.

The most important recent stage in the history of Italy's legislation on disability, as many of the articles included here note, has been its ratification in March 2009 (Law 18) of the Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol, adopted by the United Nations at the end of 2006 and opened for signature in March 2007. Originally developed through a process of wide consultation with DPOs and experts from several countries, including Italy, the CRPD is a powerful treaty. Once a state has both signed and ratified it, its government is obliged to take the necessary steps to implement its norms.

These include the right of persons with disabilities to education, to health, to full and effective participation in society and access to justice. In Italy ratification was promptly followed by the setting up of a body whose official remit has been to oversee implementation of the CRPD and to report on progress: the Osservatorio Nazionale sulla condizione delle persone con disabilità (National Observatory on the condition of persons with disabilities).

Giampiero Griffo assesses, in his article, the historic importance of the CRPD and the role of the Osservatorio. He sets the CRPD against the background of earlier conceptions of disability, and the ideas of justice that corresponded to them, to show just how decisively it moves beyond them. The older models all conceived, in different ways, of disability as a *lack* or *deficit* in the individual person and they responded by offering compensations or assistance matched to that deficit. This approach is still expressed, for instance, in the standard policies and procedures for assessing people's entitlement to state benefits on a carefully calibrated scale of degrees of disability: from minor to major sensory or motor impairments, from some to no autonomy in performing daily tasks, and so forth. The newer view, expressed in the CRPD, moves decisively away from this 'medical model' by understanding disability not as a condition inherent in people's bodies but as the product of negative social attitudes and barriers: the 'social model' of disability. The CRPD consequently places the emphasis squarely on removal of barriers and not on individual limitations. Some interpretations of the CRPD have argued that disability is not only a product of social attitudes and barriers but is an interaction between bodies and society (the 'bio-psycho-social model'). In other words, it may be said that people with disabilities do have physical or intellectual *impairments* and these sometimes (although not always) require particular medical treatments or support, but their *disability* consists in the way their impairments are viewed and dealt with by society. Whatever one's interpretation of the CRPD, however, once a UN member state has signed and ratified it, its policies and collective attitudes need to be aligned with it and it must work towards the elimination of barriers to the full inclusion of people with disabilities.

Rita Barbuto and Emilia Napolitano, in their article on women with disabilities, welcome the fact that the CRPD moves beyond a universalising and gender-neutral language of disabled people's rights and recognises the specific multiple discriminations experienced by women and girls with disabilities. They review a number of European Union research projects, to which DPI Italia (the Italian section of Disabled People's International) contributed, which highlighted different kinds of violence against women with disabilities, and then move on to a discussion of how DPI Italia is promoting peer counselling among women as a tool for their empowerment and social inclusion.

The article by Francesca Ortali, Giampiero Griffo and Simonetta Capobianco gives an example of the work that Italian NGOs have been doing internationally in supporting CBR programmes. This is an important dimension of Italian action on disability rights, given that, according to World Health Organization estimates, 15% of the world's population live with a disability and 80% of disabled people live in developing countries, where they are much more likely to live in poverty than non-disabled people (WHO 2011, 29 and WHO 2006). CBR was initially developed by the WHO in the 1990s as a way of providing medical and other services in low-income countries for people with disabilities at community level rather than through institutions that were often distant from their homes. It has evolved since then into a multi-pronged strategy to enable people with disabilities to participate fully as citizens within the communities in which they live, reducing their poverty and providing all necessary support and services in the community itself. The move towards CBR has been enhanced by the CRPD, with its emphasis on the disabled person's rights.

The two articles in this issue by non-Italians both consider how far one may speak of a distinctively Italian approach to, respectively, disability studies and representations of people with disabilities in films. Kate Noson suggests that a distinctive Italian inflection on disability studies may be emerging in the work of a number of theorists and activists and in the concepts of *superabilità*, *diversabilità* and *transabilità*. Sarah Patricia Hill applies recent work in disability studies to some contemporary Italian films, considering the ways in which they represent disability and focusing in particular on Andrea Molaioli's *La ragazza del lago* (2007).

As a final point, we invite readers of *Modern Italy* to reflect on the fact that modern Italy not only has a strong tradition of activism and action on disability but also, in its history, some well-known citizens with disabilities. The equestrian statues of Giuseppe Garibaldi that populate squares all over Italy are more familiar than the sepia photographs of him standing with a stick or seated in a wheelchair and they have allowed Italians to forget that their most celebrated nineteenth-century man of action was disabled for much of his adult life. Giacomo Leopardi and Antonio Gramsci, both of whom became physically impaired at a young age as a result of extrapulmonary tuberculosis, have undergone a different posthumous fate: that of being slotted into the stereotype of the brilliant creative mind 'transcending' a disabled body, like blind Milton or deaf Beethoven. Yet anyone who has actually read Leopardi or Gramsci knows that their intellectual trajectory and at least some elements of their world-view were directly connected to their experience of living *in* an impaired body, with the associated physical pain and discomfort. A similar point may be made about Alda Merini and Amelia Rosselli, two women whose poetry became closely entwined with their experiences of mental illness and institutionalisation. In other words, one should not celebrate these individuals for what they achieved 'despite' their disability. One should celebrate them for what they achieved. This is ultimately what is exemplary about them: not their 'exceptionality' but their ability to live and work with their disabilities and to exercise their right to full inclusion in society – a condition and a right they share with the millions of ordinary inhabitants of Italy living with disabilities today.

## Note

1. The cases that got the most media coverage in the 1960s were those of the Rifugio Maria Assunta in Cielo, Prato, directed by Father Leonardo (Giovanni Pelegatti), the Istituto Privato Santa Rita in Grottaferrata, near Rome, directed by Maria Diletta Pagliuca, and the Sant'Orsola in Catanzaro, directed by Pasquale Giannini. All three directors were found guilty. Other institutions investigated in the same period were the Preventorio Villa San Giusto and the Collegio Lenassi in Gorizia, the Villa Giardini in Casinalbo (Modena), the Casa Don Guanella in Lecco, the Suore Missionarie del Lavoro del Cuore Immacolato di Maria in Bologna and the Casa delle Fanciulle in Caltagirone (Catania). The exposure of conditions in these institutions led to the setting up, in December 1968, of a Parliamentary Commission of Inquiry into the state of institutions for children and adolescents (see *Atti Parlamentari* 1968). On the history of abuse at the Istituto Santa Rita see the recent reconstruction by Massimo Polidoro (2010).

## Notes on contributors

**David Forgacs** is Guido and Mariuccia Zerilli-Marimò Professor of Contemporary Italian Studies at New York University. He taught formerly at University College London, Royal Holloway, Cambridge and Sussex. His most recent book is *Italy's Margins: Social Exclusion and Nation Formation in Italy since 1861* (Cambridge University Press, 2014). His other publications include *Italian Culture in the Industrial Era, 1880–1990* (Manchester University Press, 1990), *Mass Culture and Italian Society from Fascism to the Cold War* (with Stephen Gundle, Indiana University Press, 2007) and *The Antonio Gramsci Reader* (Lawrence and Wishart, second edition 2000).

**Rachele Tardi** is Representative of Light for the World (LFTW) to the United Nations in New York. LFTW is an international confederation of national development NGOs committed to improving the quality of life and advocating for the rights of persons with disabilities. She holds a PhD from University College London. She worked formerly on community-based rehabilitation in Ethiopia, on inclusive education in Indonesia and as Global Child Participation Advisor for Save the Children UK. Her publications include *Best Practices for Including Persons with Disabilities in all Aspects of Development Efforts* (UNDESA, 2011) and *The Right of Children with Disabilities to Inclusive Education* (World Vision, 2012).

## References

- Atti Parlamentari. 1968. *Camera dei Deputati. V Legislatura. Documenti. Disegni di legge e relazioni. N. 799. Proposta d'inchiesta parlamentare. 23 dicembre 1968.*
- Crainz, Guido. 2003. *Il paese mancato: dal miracolo economico agli anni Ottanta.* Rome: Donzelli.
- Eurostat. 2008. *Statistics in Focus: Social Protection in the European Union.* Luxembourg: Office for Official Publications of the European Communities.
- Piro, Franco, and Lia Gheza Fabbri. 1986. *La carrozzina e il presidente. Storia di un handicappato: Franklin Delano Roosevelt.* Venice: Marsilio.
- Polidoro, Massimo. 2010. *Eravamo solo bambini.* Milan: Piemme.
- Schianchi, Matteo. 2012. *Storia della disabilità. Dal castigo degli dèi alla crisi del welfare.* Rome: Carocci.
- Shakespeare, Tom. 2006. *Disability Rights and Wrongs.* Abingdon and New York: Routledge.
- Shakespeare, Tom. 2013. *Disability Rights and Wrongs Revisited.* Abingdon and New York: Routledge (revised and expanded edition of Shakespeare 2006).
- WHO. 2006. "Disability and Rehabilitation. Global Programming Note 2006–7." [http://www.who.int/nmh/donorinfo/vip\\_promoting\\_access\\_healthcare\\_rehabilitation\\_update.pdf.pdf](http://www.who.int/nmh/donorinfo/vip_promoting_access_healthcare_rehabilitation_update.pdf.pdf)
- WHO. 2011. *World Report on Disability.* Geneva: World Health Organization.