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## Associations of people with disabilities in Italy: a short history

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Voluntary associations of persons with disabilities have played an important role in bringing issues related to disability onto the national agenda in Italy in the absence of effective provision by the state or representation by other bodies, such as the political parties and trades unions. At the same time, the nature of Italy's welfare state – weak, clientelistic, particularistic – and its way of conceiving disability as a set of bodily deficits has also shaped the character of disabled persons' organisations in Italy and the ways in which they have framed their demands and policies. These organisations have tended either to represent fragmented subsets of people with disabilities or, more recently, to form large federations that, while they reflect a more comprehensive understanding of disability, have left some categories of people with disabilities feeling excluded or under-represented

**Keywords:** voluntary associations; disabled persons' organisations; CRPD, welfare state; particularism

### Introduction

Voluntary associations formed by people with disabilities and their family members have played a key role in many countries in getting the question of disability onto the social and political agenda. In Italy they have been particularly important because the welfare state there has been structurally weak and has made limited provisions on disability. From the early twentieth century onwards it has been voluntary associations that have largely represented people with disabilities in Italy and have given social and political legitimisation to disability issues. Disabled people are not the only social subjects who have gained recognition through direct involvement in voluntary associations. Women, workers and immigrants, among others, have also made significant use of them. However, the history of disability has yet to become the object of public reflection and of political as well as academic analysis. In this article I shall map out the evolution of disability associations over the last hundred years, drawing attention to some notable events and problematic aspects.

### Associations and the welfare state legacy

Disability associations have always had to act in relation to other collective subjects: representatives of the state, of employers and workers (employers' associations and the trade union movement) and the large and highly diversified population of people with disabilities

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themselves. It is through their work with these three different sets of people that voluntary associations build their identities as well as performing their intended functions. The backdrop against which their actions take place is the nature of the Italian welfare state itself, as it came to take definitive shape after the Second World War, but also in its precursor forms.

The Constitution of the Italian Republic (1948) established the principle of equality of citizens and set out the tasks of the state. Article 3 states:

All citizens have equal social dignity and are equal before the law, without distinction of sex, race, language, religion, political opinion, personal and social conditions.

It is the duty of the Republic to remove those obstacles of an economic or social nature which constrain the freedom and equality of citizens, thereby impeding the full development of the human person and the effective participation of all workers in the political, economic and social organisation of the country.

The ‘personal’ conditions mentioned here may be understood as including all forms of disability – physical, intellectual, relational, psychic and sensory – whatever their origin. Article 38, which sanctions the fundamental right to maintenance and social assistance, constructs, within the egalitarian universe posited up to that point, two separate categories of people: workers, and those unable to work and without the means to support themselves. Each of these two categories has specific rights:

Every citizen unable to work and without the necessary means of subsistence is entitled to welfare support.

Workers have the right to be assured adequate means for their needs and necessities in the case of accidents, illness, disability, old age and involuntary unemployment.

In the light of this distinction in Article 38 between workers and those considered unable to work, how should we then view Article 3, which sanctions the full ‘participation of all workers in the political, economic and social organisation of the country’? Do non-workers, that is to say those unable to work, not have a right to full participation? What is the ‘full development of the human person’, sanctioned by Article 3, if it does not involve full participation for everyone? Article 38 responds to these distinctions by introducing a number of specific rights. It nevertheless creates a void and introduces an interpretive variable that leaves it up to the law to determine the boundary between who may participate in the life of the community and who, being unable to provide for himself or herself through work, must be subjected to specific regimes which, in practice, invalidate the equality of all citizens proclaimed by the Constitution.

The welfare state, conceived in this way, thus consists of two separate planes arranged hierarchically: the higher one concerned with work, the lower with assistance. The evolution of public policy on disability has taken place across the distinction between these two planes, between these two distinct categories of citizens. However, if the distinction between work for some and assistance for others is common to the welfare state model itself, as it has been established in all Western countries, each country has nevertheless developed its own national variant of the model. This is how Ugo Ascoli describes the Italian version:

Our welfare state corresponds above all to a *particularistic* model. It is also . . . a model that rests largely upon *patronage cultures*, it is highly *dualistic*, and it depends above all on *transfers of income* rather than on services; . . . it is based mainly on a *familistic, paternalistic* and *patriarchal* culture. The fundamental characteristics of this model have their roots in the nineteenth century and are clearly visible in the social and political history of that era as well as in the first decades of the twentieth century. They also underlie the social policies of the most recent decades. Of course, fifty years of the history of the Italian Republic have not gone by in vain. New questions, new collective actors, new

cultures and new interventions have followed each other. However, I would emphasise that the underlying characteristics are still the same. All of this goes towards explaining why it is so difficult to make real changes to the constituent elements of citizenship in our country. (Ascoli 2002, 215)

The roots of this model lie in the earliest forms of social protection introduced in the late nineteenth century:

From that moment onwards all public interventions of a social nature have always had, as their reference point, a specific category or group, with the effect that social policies have assumed a *particularistic* character, in which services are strongly differentiated according to who is receiving them. We have thus seen the emergence and consolidation of a system of social protection in which the majority of services and programmes are calibrated according to the 'status' acquired by the individual through participation in the labour market. This is a persistent element that continues to characterize the underlying structure of our system, even after half a century of often innovative programmes, social mobilization and campaigns for reform. (Ascoli 2002, 216)

This history enables us to see more clearly the situation that associations of disabled people have been faced with in Italy: part of their work has consisted in acquiring a role as a 'particular subject', a specific status or identity that allows them access to the welfare state. The whole history of the welfare system in relation to disability has been dominated by this dynamic and by the question underlying it: what is disability? Who are the people that, in relation to a specific condition, can be defined as disabled and who therefore may legitimately make use of particular services provided by the welfare state? To which services and funds are disabled people entitled? It is within the logic of these 'stakes' that the world of associations moves, in relation to the three collective subjects that mark out its sphere of operation: representatives of the state, employers and employees, and disabled people.

In the same way, the world of voluntary associations is constantly obliged to position itself in relation to two other elements that characterise the welfare state in its dealings with disability, namely 'benefits' and 'compensations'. These are based in turn on a number of legal provisions that go back to before the beginnings of the welfare state and are rooted in practices that not even the 1948 Constitution was able to neutralise: a substantial separation between the world of the disabled and that of other citizens; a practice of measuring degrees of 'bodily damage' for different categories of disability; a fragmentation of the law for a world of disability that is itself conceived as a fragmentation of categories defined by particular pathologies and impairments; a twin-track system of benefits for those impaired by military causes and those impaired by other causes; the payment of minimal economic indemnities (for certain officially recognised categories) as a form of compensation for impairments. Within this general framework we need more detailed historical studies in order to understand better the work carried out by particular social actors – politicians, parties, employers, workers, unions, civil society movements, associations of disabled people and their families – around the disability legislation passed (or not passed) in the last 50 years. It would also be useful to know who, in each case, supported that model and how. Were there attempts to invalidate it or construct a particularistic variant of it? Who was involved, both visibly and behind the scenes? What were the main themes around which debate, opposition and consensus were created?

### **Phases of the associative movement**

The history of associations involved with disability began towards the end of the First World War – the event that, together with the industrial revolution and the development of the factory system, made disability a 'side effect' of modernity and pushed 'mass disability' onto the social

stage. This meant a greater number of disabled people compared with previous centuries and the consequent need for measures that could deal with ‘inabilità’ (as it was called then) in a broad sense. With the creation in March 1917 of the Opera Nazionale per l’Assistenza e la Protezione degli Invalidi di Guerra the ‘social question’ of disability began to gain visibility, framed in the rhetoric of the glorious war invalids, of whom Enrico Toti, already disabled when he was killed in action at the front, became one of the most prominent symbols (see Bracco 2012). This was followed by the first legislation obliging public and private firms to hire people with disabilities (August 1921) and by the provisions in the 1923 Education Act (the ‘Riforma Gentile’) on education for the blind and the deaf.

It was in this context that the first associations linked to disability emerged in Italy, most of them founded by people who had direct personal experience. In January 1917 Aurelio Nicolodi, who had become blind during the war, created the Associazione Nazionale per i Ciechi di Guerra. After a few months this merged with the newly formed Associazione Nazionale fra i Mutilati e gli Invalidi di Guerra (ANMIG). The following year saw the creation of what would become the Lega Proletaria Mutilati Invalidi Reduci Orfani e Vedove di Guerra, which soon opened a number of branches in northern Italy (Isola 1990) and about which Antonio Gramsci wrote in 1919 that it represented ‘the first, large-scale attempt to organize the peasant masses’ (1973, 39). The general secretary of the Lega Proletaria Mutilati was Gaetano Pilati, a building contractor and Socialist, who had lost an arm during the First World War. In 1922, following the first Convegno dei Sordomuti italiani (Italian Conference of Deaf-Mutes), held in Genoa in 1920, the Federazione Italiana delle Associazioni fra i Sordomuti (FIAS) was founded on the initiative of Giuseppe Enrico Prestini and in 1924 the Unione Italiana Sordomuti was created. During the night of 4–5 October 1925, Pilati, who had by then become a prominent Socialist political figure in Florence, was murdered by three Fascist assassins. It was the ‘Matteotti affair’ of disability because from that moment on the associations of disabled people could survive only by becoming fascistised. The entry ‘Invalidi e mutilati’ (‘Invalids and maimed’), written in 1934 by Carlo Delcroix, president of the ANMIG, and published in Volume 24 of the *Enciclopedia italiana* is a good example of how this question was co-opted by the Fascist apparatus and Fascist culture. Little is known, as yet, about whether political alternatives to the Fascist position found expression within the associations at that time, but closer analysis may yield in the future a more nuanced picture of attitudes then towards disability.

Other associations representing specific groups of people emerged in the same period. In 1932 the Ente Unico in Rappresentanza dei Sordi Italiani was founded and it requested official government recognition (this was accorded in 1942, when the Ente Nazionale Sordi, ENS, was created). In 1933, the Associazione Nazionale fra lavoratori Mutilati e Invalidi del Lavoro (ANMIL) was founded in Milan. It had a very short life (it would be reconstituted in 1943) because in 1934 the people present at its headquarters were arrested and it was closed down, even though those arrested were subsequently released as a result of appeals. Some of its functions (medical care, professional retraining and material support for those with industrial injuries, organisation and protection for workers) were taken over by the Istituto Nazionale per l’Assicurazione degli Infortuni sul Lavoro (INAIL, National Institute for Insurance against Accidents at Work), formed in 1933 following the creation of a single national fund for those affected by workplace accidents (Cassa nazionale per gli Infortuni sul Lavoro).

It is clear how, in this early phase, a strongly category-based view of disability, upheld by the associations themselves, developed within the corporatist organisation of employers and workers promoted by the Fascist regime. Even the medical criteria adopted for identifying ‘inabilità’ contributed to this particularistic view. From the 1920s onwards the first tables for

measuring ‘anatomical damage’ were elaborated and applied. A member of the armed forces or a worker (these were the only two categories that were recognised) who had undergone permanent anatomical damage in the exercise of his functions was to receive compensation in relation to the gravity of the damage, as certified by a medico-legal college.

The associations underwent considerable development after the Second World War, again as a result of the efforts of the people directly interested and their family members, as Italy’s embryonic welfare state began to take shape. In March 1945 the *Unione Nazionale Mutilati per Servizio* was formed in Rome (it would be formally recognised as an *ente morale*, a charitable institution, in 1947), although its origins in fact dated back to 1937 and to the efforts of Andrea Gaspari, an army officer impaired after being injured during a military exercise.

The new question that emerged strongly, however, in the decades after the Second World War was the recognition of different forms of ‘inabilità’ and of categories of persons whose impairments were the result neither of military or industrial injuries nor of a sensory kind. An important part of the world of associations that formed at that time was driven by the need to gain juridical and medical recognition for these other categories of people, in order to support the development of treatments and services appropriate to them. Individuals and families affected by disabilities seemed to be caught up in the contradiction between an Italian society that was changing at a dizzying speed and their own condition, unchanged since pre-welfare state days. Ever since that time disability had appeared to be almost exclusively the province of those directly interested in it. The mass political parties did not include it on their agenda.

If we try to identify the main outlines and contradictions in the history of Italian associations of disabled people we can say that, despite their fragmentation, they have always confronted their own condition directly rather than delegating it to others. This has often taken place through forms of particularism that have mirrored a non-universal, ‘category-specific’ conception of disability and it is through these forms that the different collective actors, their spokespersons, and the welfare state as a whole, have developed. Yet this particularism (of which the associations of people with disabilities are often accused) is the result of a peculiar set of dynamics that needs to be understood. It is the result of their shared awareness of specific issues but at the same time of struggles for the recognition of their particular condition. It is the result of a longstanding cultural and political neglect of disability by the traditional ideologies and movements: a gradual ‘taking shape’, through small increments, with a constant risk of collapsing into ‘ghettoes’ constructed by both those on the outside and those on the inside (according to the binary ‘you disabled–we disabled’). It is the result also of the human and social specificity of individual experiences (what does a person with intellectual disability have in common with a deaf person other than the fact of being a person or of being differently stigmatised?) It is the result of the fact that often the condition of disability is lived with great difficulty; it is a grief that is never really and definitively worked through. It is the result of being continuously considered (in the world of public services and the social world that each of us constructs around ourselves) inferior citizens and individuals.

Particular associations continued to develop through the 1950s and into the 1960s. In 1954 the *Associazione Italiana Assistenza Spastici* (AIAS) was set up in Rome on the initiative of a group of parents of children with cerebral palsy. In 1956 Alvido Lambrilli founded, in Taranto, what was to become the *Associazione Nazionale Mutilati e Invalidi Civili* (ANMIC), officially recognised in 1965 as a public institution (*ente di diritto pubblico*). In October 1957 a national association of people with invalidities caused by polio, *Associazione Nazionale Invalidi per Esiti di Poliomielite* (ANIEP), was founded at the University of Bologna, although this in fact developed out of the *Associazione di invalidi civili in Italia*, created in 1945, which in turn had

its origins in an association formed in Bologna in 1939 by Giordano Bruno Guidi and about 40 people with physical disabilities. In March 1958 the Associazione Nazionale Famiglie di Fanciulli Minorati Psichici (ANFFAS, National Association of the Families of Children with Intellectual Disabilities) was formed in Rome under the pressure of a group of parents led by Maria Luisa Ubershag Menegotto and in 1964 it was recognised as an institution with juridical status (*ente con personalità giuridica*). Since 1988 this has also been the body representing people with intellectual and relational disabilities in the medical commissions that ascertain invalidity benefits. In 1960 the Associazione Nazionale Invalidi Civili (ANICI, National Association of Civil Invalids) was created and in December 1961, in Trieste, Federico Milcovich founded the Unione italiana lotta alla distrofia muscolare (National Union for the Fight against Muscular Dystrophy, UILDM), which has also been involved in scientific research.

In 1962 a unified platform of these associations managed to obtain the first law on job placement for people with invalidities. The law also envisaged the collaboration between associations of people with civil invalidities. In 1965 ANMIC was recognised as the sole representative of this category of people. ANFFAS and AIAS represented people with graver disabilities who were largely excluded from the social stage.

The moment of maximum visibility of associations of people with disabilities in Italy in this period, between the mid-1950s and late 1960s, came with the series of street demonstrations known as *marce del dolore* (pain marches). These were events of great symbolic significance, which placed the political and social issue of disability firmly on the agenda of public debate and managed to accelerate a number of important legislative provisions: the laws on benefits and on compulsory work placement, the framework law of 1971. The first demonstration took place in May 1954, when a group of blind people, who later obtained the support of the UIC (Unione Italiana dei Ciechi, founded in 1920) and of a number of spontaneous committees, marched from Florence towards Rome. In 1961 the first ‘marcia del dolore’ to advocate for the demands of civil invalids gathered in Rome outside the Parliament building in Piazza Montecitorio. A second demonstration in Rome in 1964 focused on work placement of civil invalids, and on economic and medical assistance and prostheses. In January 1968, in response to police attacks against a pain march of civil invalids, there was a 10-day hunger strike outside Parliament.

In the same period, particularly in the UK and USA, rights-based movements of people with disabilities developed as part of the wider set of movements of protest and emancipation of traditionally ‘subaltern’ groups, including women, lesbians and gay men and ethnic minorities. Self-assertion by these groups took place simultaneously within a number of political and intellectual movements, where they challenged the inability of the ‘classical’ ideologies and social critiques to take them into account, to recognise the questions they were raising and the forms of marginalisation they experienced. The social and political culture that now started to take shape was based on the concepts of human and civil rights. According to this outlook, the person with a disability could no longer be conceived according to a medical and functionalist paradigm, as someone who deviated from normality, and their social experience could no longer be conceived in negative terms, on the basis of personal attributes, without taking account of their presence (even in its difference) or the contextual factors that produce exclusion and often negate a person’s intrinsic human rights. The experiences and approaches that developed out of these movements transformed the world of disability, equipping it with new tools that were linked both to a language of rights (equality, equal opportunity with all other citizens, self-determination) and to new interpretive models. I am referring, of course, to the ‘social model of disability’, whose earliest formulations were those of Paul Hunt in the 1960s (Hunt 1966), later developed by scholar-activists with disabilities who in London in 1976 framed the ‘Fundamental

Principles of Disability' and formed the Union of the Physically Impaired Against Segregation (UPIAS), and to the creation in 1972, by Ed Roberts in Berkeley, California, of the first Center for Independent Living.

The wave of social and political activism from the 1960s to the late 1970s swept through the world of disability in Italy too. There were new demands for de-institutionalisation, integration in schools and insertion into society. The problems linked to the multiple 'categories' of the disabled increased. For instance, there was opposition to the ANMIC because it failed to represent or recognise 'civil invalids', a large and heterogeneous population including people with motor impairments, intellectual disabilities and progressive and genetic diseases, whether mild, moderate or serious. Many movements arose out of experiences in the voluntary sector, both lay and religious, where there was an increasing number of cooperatives offering support at community level (in antithesis to 'total institutions') and help with access to the labour market. This movement was strongly 'in phase' with the movement to close mental asylums (*manicomi*). For example, at the conference organised in September 1977 by Franco Basaglia in the grounds of the psychiatric hospital of Trieste there were some groups who had been brought along by the Comitato Handicappati Organizzati in Naples. At the same time some parts of the disability movement began to argue for the need to break away from the logic of 'categories' and the forms of assistance and compensation that underpinned the Italian welfare system and move towards a different system that promoted people's rights and opportunities.

In 1966, 13 people with disabilities and a young priest, Don Franco Monterubbianesi, founded the Comunità di Capodarco, an experiment in communal living in an abandoned villa in Fermo in the Marche. In 1968 the Associazione Italiana Sclerosi Multipla (AISM) was created. In 1973 an association of families for the defence of the rights of deaf people, Famiglie Italiane Associate per la Difesa dei Diritti degli Audiolesi (FIADDA), was formed. In 1976 Rosanna Benzi, who had lived inside an iron lung for 29 years, began to edit the magazine *Gli Altri (The Others)*. This and the news bulletin *Informazione e riabilitazione (Information and Rehabilitation)*, published by the Fondazione Don Gnocchi and edited by Piergiorgio Mazzola, were the first attempts in Italy to get information about disability out beyond a self-referential circuit to a wider readership. Benzi's magazine launched a series of campaigns to raise awareness of issues related to disability and social marginalisation, including a campaign against barriers in the built environment and others regarding sexuality, tax relief and orthopaedic devices. In October 1977, in Milan, the first conference in Italy on disability and sexuality was held (Tessari and Andreola 1978). The radical nature of the arguments put forward there have, unfortunately, never been matched in any of the numerous subsequent publications and conferences on the same subject. The question of sexuality rarely figures on the list of demands currently made by the associations at a political level; it has remained an aspect of lived experience on which these organisations have made relatively few reflections.

Rosanna Benzi's experience led to the founding in 1979 of the Lega Nazionale per il Diritto al Lavoro degli Handicappati (National League for Right to Work of the Handicapped). A few years earlier, in 1976, the Fronte Radicale Invalidi, which later became the Lega Arcobaleno (Rainbow League), had been founded by Bruno Tescari. It argued for the right to services and access to work and for the overcoming of architectural barriers. In 1979 a small group of people with paraplegia and tetraplegia founded, in Rome, the Associazione Italiana Paraplegici, with the aim of creating an organisation that would look after and promote the quality of life of people with medullary lesions. 1979 also saw the founding, in Milan, of the Lega per i Diritti degli Handicappati (League for the Rights of the Handicapped) (LEDHA), which brought together associations across the region of Lombardy with the aim of defending the rights and dignity of



people with disabilities and their families, and of the Associazione Bambini Down (Association of Children with Down's Syndrome), later renamed Associazione Italiana Persone Down (Italian Association of Persons with Down's Syndrome).

In the 1980s, alongside the debate over laws and regulations another debate took shape concerning the welfare state in relation to disability and the particular characteristics that made it such a complex, fragmented and patchy system, with many provisions not being implemented. In 1980 a large number of associations, led by the Lega Nazionale per il Diritto al Lavoro degli Handicappati, drafted a people's bill (*proposta di legge di iniziativa popolare*) aimed at reforming the law on compulsory work placement for people with disabilities. The bill got 120,000 signatories and in April 1980 it was presented to Parliament and to the President of the Republic, Sandro Pertini. From this time onwards there was a notable growth in the number of associations, linked to the more general expansion of the voluntary sector at the time, and this raised new questions. On the one hand, the number of people with disabilities and family members taking part in associations was greater than ever before, but on the other hand there was fragmentation of demands, and this created a need for stronger linkages between associations, at any rate on some of the big questions that affected all people with disabilities. The same dynamic was at work at an international level. In 1981, International Year of Disabled Persons, the first meeting was held in Singapore of Disabled People's International (DPI), a worldwide organisation aiming to form a united front on general questions regarding disability. The organisation was quickly recognised as an interlocutor by international agencies and institutions and it managed to pull together demands coming from different parts of the disability world, but at the same time it had a propulsive effect on the system of associations at national level.

In Italy, the idea of creating 'united fronts' at regional level steadily gained ground during the 1980s. Federhand drew together the disability associations in Campania, the Coordinamento Sanità ed Assistenza (later Comitato Unitario Invalidi) united those in Piedmont, the Comitato Unitario Invalidi those in Tuscany and Coordinamento H those in Sicily. The drawing together of these associations responded to a need for direct and active involvement by people with disabilities and their families in framing policies and interventions regarding them, as had already happened in a number of cities – Genoa, Milan, Bologna, Rome, Naples – where associations had managed to get consultative bodies set up at local level and as would happen later in a number of regions after their powers were increased. In Liguria, Friuli Venezia Giulia and Marche regional consultative bodies involving persons with disabilities were created.

While these united fronts were being created there was growing frustration in the world of disability associations with the variations in speed at which support was delivered through the Italian welfare system, where widely differing levels of allowance and benefit were accorded to different types of disability. There was frustration, too, with the ways in which the larger associations – the privileged partners in the dialogue with political institutions – focused more on their own interests as associations than on the rights of persons with disabilities and their families. A number of families of people with serious or very serious disabilities left the associations that had traditionally represented them in order to fight against institutionalisation, for a mobility allowance and for recognition of the work of carers. A group of families in Rome formed the *Unione Famiglie Handicappati e Coordinamento Romano*, which, although not formally structured as a national organisation, was recognised by very many families all over Italy, who delegated powers to it. It was in this context that the expression 'dopo di noi' ('after us') began to be used to identify a central problem: that of the structures and services that would be responsible for the lives of people with disabilities after their parents died. Large institutions

were excluded as the solution to this problem. It was also recognised that services and structures had to be created while the parents were still alive: ‘durante noi’ (‘while we are here’).

The 1980s also saw the emergence of new organisations linked to types of disability that had not previously been adequately diagnosed or treated. In 1983 an association for motor neurone disease, the Associazione Italiana Sclerosi Laterale Amiotrofica (AISLA) was formed, and in 1985 an association of parents of persons with autism, Associazione nazionale genitori soggetti autistici (ANGSA). Three other new associations arose after their members split off from ANMIC: Unione Nazionale Mutilati e Invalidi Civili (UNMIC), Libera Associazione Invalidi Civili (LAIC), and Opera Nazionale Mutilati e Invalidi Civili (ONMIC). The same period also saw another phenomenon that was not always transparent: a number of companies with strong interests in the production and sale of assistive devices supported the formation of associations whose main purpose was to secure continued control over their sectors of the market.

The preparation of the *legge quadro* (framework law) of 1992 (Law 104) marked another turning point in the history of Italian disability associations. Over 30 of them were involved in the consultative working group set up within the Department of Social Affairs. The strong differences between them that came to a head in the process led to the formation of two large federations: FISH (Federazione italiana per il superamento dell’handicap – Italian Federation for the Overcoming of Handicap) in 1993, and FAND (Federazione tra le associazioni nazionali dei disabili – Federation of National Associations of the Disabled) in 1997. The latter grouped together the ‘historic’ associations: ANMIC, UIC, ENS, ANMIL, UNMS.

Italian sections of the international organisations ENIL (European Network on Independent Living) and DPI were formed respectively in 1991 and 1994. As well as the demands arising from the international context in which they operated, these Italian associations also drew inspiration from the work on human rights being carried out within the United Nations context, which I shall discuss below. It was in the same period, the early 1990s, that allegations about ‘bogus claimants’ of disability benefits began to raise suspicions that illicit networks of citizens, members of the medical profession and even disability associations were involved in fraud and abuse of the system. These abuses are part of the wider context of disability benefits that function as ‘social shock absorbers’. The percentage of people who benefit from them is higher in the less developed parts of the country, where the indemnity often functions not as an intervention in favour of the person with a disability but as a means of support to families in economic difficulties (Gori 2010). The phenomenon of ‘false invalids’, as well as being a crime that is really perpetrated by some individuals, in league with compliant commissions of doctors and sometimes also organised criminal groups, is long established, but recently the media have hugely inflated its scale, allowing people to forget that in reality it involves only 4% of persons with disabilities, in order to justify policies and arguments for cuts to benefits in whole areas of the welfare state.

In the 1990s the associative movement as a whole sought to deal with some of the big longstanding issues: the limitations of the Italian welfare system in relation to disability; the different speeds at which the welfare state operated according to the different categories into which disability was divided, with some categories reached by its services and others reached only partially or not all; the continued use of cash to people with disabilities as a ‘social shock absorber’ and the consequent traffic in illicit benefit payments; the emergence of different positions from one association to another on social policies or on the relations between disability associations and voluntary associations, the so-called third sector, as well as trades unions. In the mid-1990s, with new demands regarding disability emerging in Europe, networks of associations in Italy began to engage in dialogues both with the European networks and with

institutions. The Consiglio Nazionale sulla Disabilità (CND), a member of the European Disability Forum, and the Consiglio italiano dei disabili per i rapporti con l'Unione europea (CIDUE – Italian Council of Disabled People for Liaison with the European Union) were created. The presence of several organisations reflected the division between the large groups of associations on ideas and cultures of disability that had emerged clearly in the 1980s and had been formalised in the 1990s.

### **Problems of the recent scenario**

In the course of the 1990s there was a great increase in the number of local associations (often linked to national associations), and this was a sign both of the considerable expansion of the voluntary sector in that period and of increased direct action by people with disabilities and their families. It also showed the importance of grounding demands for the fulfilment of rights and needs in the socio-political debates taking place in individual areas, from assistance to free time to sport, in relation to specific demands and to the agencies providing social and welfare services at local level, from political circles to schools. The associations took up a range of different positions in these contexts. Sporting activities are understood as occasions for play and sociability, in other words for sport in the full sense, and not simply as therapeutic pretexts. As for education, the movement of family members that had played such an important role in the 1970s in demanding the law on integrated schooling (1977) continued, albeit with less intensity. In the same period, the expansion of Internet use gave rise to new forms of communication concerning disability issues, new ways for the associations to organise themselves, the creation of informal organisations and the development of campaigns around single issues. At times these campaigns led to an expansion of the issues dealt with by the associations; at times they were more inward-turned or even family-centred. During this decade, the large associations had now become political actors engaging in dialogue with the worlds of politics and public administration and new demands arose for representation of people with disabilities through forms of direct political participation. The latter included the Movimento Italiano Disabili (MID), Associazione Nazionale Italiana Diversamente Abili (Italian National Association of the Differently Abled – ANIDA) and Movimento Europeo Diversabili Associati (European Movement of Associated Differently Abled Persons – MEDA).

In the last few years the large associations have supported Italy's ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), which took place in March 2009, and they have started to play an active part in the Osservatorio Nazionale sulla condizione delle persone con disabilità, set up in the wake of ratification (see Giampiero Griffo's article in this issue). The CRPD has provided a decisive impetus in Italy for the sharing of concepts and languages across the different categories of disability. It has enabled a collective outlook to take shape, as never before, in a world of disability associations divided both in its large federations and at local level. At the most recent national conference on disability, held in Bologna in July 2013, it was clear from the contributions by speakers who came from the worlds of politics and public administration – at least in the language and concepts they used – that the work done by the associations on the formulations of the CRPD has spread to people belonging to those parts of the state who work most closely with disability issues. Unfortunately, however, this tendency was contradicted by ministerial statements or measures that proved to be incapable of incorporating the CRPD's provisions. This scenario reflects a wider paradox relating to disability as a whole: no legislative formulation has been more wide-ranging or more advanced than the CRPD, but the welfare state as it has been formulated in Italy since the Second World

War, with all the advances made from the 1970s to the 1990s, including in the area of disability, is now undergoing such retrenchment that even a government minister has spoken of an erosion of 'charitable welfare'. This paradox also involves the associations that on the one hand support and spread the language and concepts of the CRPD and on the other find themselves defending a welfare state that the CRPD has effectively relegated to the attic, because the risk is that, if they do not, even that will cease to exist. One of the most dramatic examples of this is the cutting of the Fondo Nazionale per le non autosufficiente (National Fund for Non-Self-Sufficient Persons), instituted in 2007, which allocated a total of 400 million euros to the regions in 2009 and only 275 million in 2013. However, there have also been cuts to local bodies, new restrictive criteria for obtaining emoluments and a campaign waged by the national insurance institute, the Istituto Nazionale della Previdenza Sociale (INPS), to reduce its number of borrowers.

It has been in this context that a number of street demonstrations have taken place, which have made clearly visible on the one hand the crisis of the welfare state and on the other the emergence of new social subjects in the world of the associations. In July 2010, FISH and FAND organised a large demonstration in Rome against government cuts. In October 2012 many disability associations took part in the demonstration organised by the network 'Cresce il welfare, cresce l'Italia' ('If welfare grows Italy grows too'). In November 2012, at a demonstration in Rome organised by the Comitato 16 novembre – a committee founded in 2010 by a number of people with motor neurone disease – the participants declared they were prepared to die in order to assert their constitutional right to medical treatment and care. This demonstration in particular was promoted and supported by new associations that do not consider themselves to be represented by the large federations, FISH and FAND, and are often in conflict with them.

The proliferation of associations, and the separation of some of them from the large federations, fits with a more general trend towards participation in civil society and a devaluation of traditional forms of representation by the 'classical' political subjects, notably the parties and trades unions. For the world of disability these new forms of participation have not been the result of a breaking away from the traditional political subjects, since the latter have always had a very marginal involvement with disability issues. Indeed, only now are they starting to deal with them. This is particularly true of a number of trade union organisations, which are now entering a field in which they have traditionally done very little, most probably because they are looking for new subjects to represent rather than because they have realised what a gap they have left in this area. If we confine our analysis just to the associations that have an explicit civil commitment to the rights of people with disabilities and to obtaining services for them and their families (leaving out, for example, the other areas where there has been a recent growth in associations, most notably sport) we can identify some underlying trends and some issues that warrant further investigation.

One of the factors that has undoubtedly raised the level of participation has been the new possibilities of communication opened up by computers, smartphones and tablets and by the new virtual communities associated with them, even though the specific forms of participation by persons with disabilities using these means remains to be investigated in detail. Another factor contributing to the recent increase in participation has been a growing awareness of individual rights. When people are unable to find adequate support or representation in existing organisations they turn to direct participation, creating their own associations and also playing a critical role within existing ones. At the same time, when individuals and families with this increased awareness of their rights are faced with a situation of shrinking provision by the welfare state and lack of the developments they had expected, one of the effects is that they

create new organisations outside the major federations, FISH and FAND. These organisations include the Coordinamento famiglie disabili gravi e gravissimi (Coordination of families of persons with serious and very serious disabilities), Comitato 16 novembre, Comitato 14 settembre, Disabili in lotta: dalla delega all'azione (Disabled people fight back: from delegation to action). As with other civil society movements, the increase in participation goes hand in hand with increased activity at local level and a focus on particular themes. For example, many groups, committees and associations have formed around the issue of the education of children with disabilities, starting with the inclusion of their own children in a local school and then expanding the network to the whole country. An example of this is the movement Genitori tosti ('Tough parents').

A few critical observations might be made, nevertheless, about this new wave of participatory activism. Just when the old associations, those that have been around for years and have joined the large federations, are starting to share a new language and new demands – those of the CRPD and the critical responses to the decline of the welfare state – and are trying to overcome particularism and the subdivision into categories, the new associations sometimes seem themselves to be instituting new kinds of particularism. By venting their frustration with the large organisations (which they accuse of colluding with the politicians, giving prominence to certain personalities, and a whole panoply of insults that can easily go public on social media, even though their political importance is ephemeral) they run the risk of cutting themselves off from a political arena where they might actually interact productively with other subjects: institutions, trades unions, people with disabilities themselves. Because it is on this politico-institutional front that the associations have now become, by right, a political subject and not just a lobby or an interest group. The difficulty that many associations have in taking on board the wider issues of the world of disability, or adopting a longer-term perspective (which, to be sure, is being continually undermined by the repeated attacks on the welfare system), could be serving the interests of a welfare state that is far from renewing itself and may just be playing the old game of divide and rule.

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