Disability in the Spanish press: from the paradigm of rehabilitation to the paradigm of personal autonomy

Abstract
We analysed discourse produced in the Spanish press on a number of issues relating to disability (accessibility, education, employment, sport and institutionalisation). The aim was to identify the underlying paradigm: that of rehabilitation or personal autonomy. The analysis was based on 435 units of analysis including news, editorials, opinion articles, reports and letters to the editor, selected from two national newspapers (ABC and El País) published between 1978 and 2012. Discourses generally evolved from reflecting a medical-rehabilitation concept of disability to a more social perspective on disability. It was necessary, however, to examine discourses and practices in different domains separately, as this evolution was not reflected in equal measure in all of them.

Keywords
Disability, press, paradigms, discourse analysis.

1. Introduction
The media’s major role in constructing reality motivated our research on how the Spanish press has addressed and projected the issue of disability. We focused our study on articles published between 1978 and 2012 in two major national newspapers: ABC and El País. The period under study thus began with Spain’s transition to democracy in the late 1970s, when intense reforms and restructuring of the public system were set in motion.

The results we obtained may seem unsurprising to us today, but they illustrate how the issue of disability evolved in Spain in line with transformations that took place worldwide. To understand this evolution, we must first briefly review the paradigms of disability.

Two paradigms currently prevail: that of rehabilitation and that of personal autonomy (Hunt, 1966; Dejong, 1979; Oliver, 1990; Casado, 1991; Palacios & Romañach, 2006). The rehabilitation paradigm supported the first guidelines of intervention to be applied to disability and was based on health-disease parameters. The problem centred on disabled individuals, as they were understood to be suffering the consequences of a disease, trauma or health condition: this justified the aim of rehabilitating people so they adapt to their environment. The disabled were institutionalised so they could receive individual treatment in accordance with medical instructions (Oliver, 1990). Disability was considered to be an individual pathology. This conception is biologicist or organicist: it presupposes the existence
of biological inferiority in cases of disability and focuses on treating a person’s weaknesses or deficiencies (Iáñez, 2010).

In the 1960s, physically disabled people coming from civil organisations, universities, and veterans’ associations formed the Independent Living movement in the United States. The physically disabled had a leading role within the movement. A new understanding of disability gave rise to the paradigm of personal autonomy, clearly reflected in the social model. In the personal autonomy paradigm, the idea of disability as an individual pathology was abandoned while the environment itself became the focus of attention: the environment was understood to be disabling and led to discriminatory processes and social exclusion (Abberley, 1987; Oliver, 1998). The focus thus shifted from individuals to the collective perspective (Rodríguez & Ferreira, 2010) and disability was conceptualised as a social construction (Iáñez, 2010), i.e. as the result of people’s interactions with the environment. It is within this environment that discriminatory processes are born. The constructionist conception thus challenged biologicism present in the rehabilitation paradigm.

The rehabilitation paradigm and the independent living paradigm are compared in Table 1 below based on Dejong (1979). This author suggested to leave behind the rehabilitation paradigm –according to which disabled people are conditioned by their pathology, which limits their participation in society–, and move towards the independent living paradigm, where the problems people with disabilities have to face can attributed to the social environment.

Table 1: Comparison of Rehabilitation and Independent Living Paradigms.

<table>
<thead>
<tr>
<th>Item</th>
<th>Rehabilitation paradigm</th>
<th>Independent living paradigm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definition of problem</td>
<td>Physical impairment/ lack of vocational skill</td>
<td>Dependence on professionals, relatives, etc.</td>
</tr>
<tr>
<td>Locus of problem</td>
<td>In individual</td>
<td>In the environment;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>in the rehab process</td>
</tr>
<tr>
<td>Solution to problem</td>
<td>Professional intervention by physician, physical therapist, occupational therapist, voc rehab counsellor, etc.</td>
<td>Peer counselling advocacy  self-help</td>
</tr>
<tr>
<td></td>
<td></td>
<td>consumer control removal of barriers</td>
</tr>
<tr>
<td>Social role</td>
<td>Patient/client</td>
<td>Consumer</td>
</tr>
<tr>
<td>Who controls</td>
<td>Professional</td>
<td>Consumer</td>
</tr>
<tr>
<td>Desired outcomes</td>
<td>Maximum ADL, Gainful employment</td>
<td>Independent living</td>
</tr>
</tbody>
</table>

Source: Dejong, 1979.

These models have not evolved chronologically: we cannot say that one paradigm has taken over the other. Rather, they have developed simultaneously, though a shift from the rehabilitation paradigm to that of personal autonomy can be observed. This transformation, which is reflected internationally within the United Nations Organization and the World Health Organization, remains ambiguous in the real world. As pointed out by Toboso (2013), practices and perceptions proper to both paradigms are embedded in different domains of intervention (whether political, legislative, work-related, educational, etc.), which is why we can say that both visions coexist.

In this article, we analyse discourse in the press expressed by different actors concerning a number of disability-related issues (accessibility, employment, education, sport and institutionalisation). The aim was to identify how practices have evolved and the underlying paradigm.
2. Methodology
The study was exploratory, longitudinal and deductive. Within the theoretical framework, the main objectives consisted in discovering the social representations of disability in the media on the one hand, and on the other, in identifying the rationale supporting discourse and practices.

The corpus was composed of selected units of analysis from the ABC and El País newspapers, published between 1978 and 201. Both newspapers had the largest circulation over the period under study. As three decades were covered, it was possible to perform a longitudinal analysis, which was one of the strengths of this research. The units of analysis were not strictly limited to news items but also included editorials, opinion articles, reports, interviews and letters to the editor.

Units of analysis were searched and selected using the search engines on the newspapers’ websites. To correctly use these search engines and remain close to the study’s objectives, we defined the “key terms” that would lead us to a diversified sample. After several attempts, the selected terms were: physically handicapped, physically disabled, physical disability and functional diversity. We assumed these terms corresponded to different historic points in time that were reflected in the written press. Although the object of study was limited to people with physical disabilities, many of the results obtained were applicable to other types of disabilities.

We compiled the units of analysis that appeared in each newspaper in a table according to each key term and year. This type of search generated duplicates that were rectified when creating the database. This table was used to establish the proportion of units of analysis to be selected for a theoretical sample of 300 units. The sample consisted of a total of 435 news items: 202 from ABC and 233 from El País.

<table>
<thead>
<tr>
<th>Year</th>
<th>ABC</th>
<th>EL PAÍS</th>
<th>Total</th>
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<tbody>
<tr>
<td>1978-1981</td>
<td>18</td>
<td>13</td>
<td>31</td>
</tr>
<tr>
<td>1982-1985</td>
<td>11</td>
<td>15</td>
<td>26</td>
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<td>1986-1989</td>
<td>28</td>
<td>11</td>
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<td>1990-1993</td>
<td>32</td>
<td>11</td>
<td>43</td>
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<tr>
<td>1994-1997</td>
<td>25</td>
<td>31</td>
<td>56</td>
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<tr>
<td>1998-2001</td>
<td>23</td>
<td>44</td>
<td>67</td>
</tr>
<tr>
<td>2002-2005</td>
<td>20</td>
<td>38</td>
<td>58</td>
</tr>
<tr>
<td>2006-2009</td>
<td>25</td>
<td>36</td>
<td>61</td>
</tr>
<tr>
<td>2010-2012</td>
<td>20</td>
<td>34</td>
<td>54</td>
</tr>
<tr>
<td>Total</td>
<td>202</td>
<td>233</td>
<td>435</td>
</tr>
</tbody>
</table>

Source: Own compilation.

We selected more news items than originally intended because we decided to include all the letters to the editor as well as interviews with people with disabilities as “additional” units. The aim was to preserve and collect the voices of persons with disabilities within the analysed media. When selecting the units of analysis, we chose units with greater discourse contents over news items in the strict sense, as their contents were more descriptive and objectively expressed.
The units of analysis were studied according to a two-fold approach: (1) content analysis, which focused on identifying the most widely used terminology and its evolution over time, the representation of men and women, the most frequent journalistic genre, the news section they were published under, and the presence and frequency of topics according to the historical point in time (Iáñez & González, 2017); (2) discourse analysis, which examined the evolution of discursive perspectives on issues such as accessibility, education, employment, sport and independent living, relating them to both prevailing disability paradigms (rehabilitation and personal autonomy).

News items were studied according to their classification by topic, taking into account the text’s main content. Nonetheless, all discourse arises within a context, so the text (“what is said”) and the context (the “moment” or “conditions” which gives rise to it) were key to the analysis: “Only in a given context do words reach their full meaning” (Cantero & De Arriba, 1997, p. 49).

3. Practices and discourse around disability in the press

3.1. From the elimination of architectural and urban barriers to universal accessibility

The first claims of a right to accessible public and private spaces emerged in the 1980s beginning with requests to suppress architectural and urban barriers. The removal of physical barriers in buildings and streets was to become a recurring theme over the years, and even persists today. It prevailed, however, in the 80s and 90s press. During the first decade under study, accessibility to other social domains such as education, employment, leisure, housing, etc. was also requested.

Some of the sector’s organisations were particularly resolved in their battle against architectural and urban barriers; they organised events and mobilisations that made them visible and enabled them to reach out to the rest of society. The suppression of these barriers was understood as a necessary step towards social integration. Signs of a social model thus began to appear, based on demands to adapt the environment. Despite being legislated, these adaptations had not been implemented in streets and public buildings, and to an even lesser extent in private buildings. In many cases, private voices denounced the presence of these obstacles. This reality continues to generate discriminatory situations today:

How much are autonomy and personal freedom worth and how much does it cost to suppress (or so it seems) the barriers that affect people with functional diversity! Indeed, we encounter all kinds of obstacles walking through the streets or using different services: pavements that are too narrow for wheelchairs to pass through, or that are not lowered, impossible ramps, shops and buildings with non-adapted entrances and interiors, counters that are too high, screens with no audio, loud speakers with no screens, faulty transport adaptations... when you live the experience or look more closely, the list becomes endless. The cost of removing these barriers and making life easier for everyone seems negligible compared to the levels of autonomy and freedom so many people would gain.

Main entities began by centring their struggle on suppressing architectural and urban barriers in urban centres, reaching lesser populated municipalities later. In turn, requests for accessibility in non-urban environments led to the conquering of new spaces people with disabilities had barely visited until then, precisely because they were inaccessible; these spaces opened up to sports, leisure, tourism, etc. In 1985, the Coordinator for the Physically Handicapped in Madrid prepared an accessibility guide for cinemas, theatres, concert halls, etc.

1 “Architectural barriers” (El País 21/12/2012).
The handicapped, who are first-class citizens, must have access to recreational areas. Public spaces, however, are not always designed for everyone. In such cases, disabled persons, at the very least, should be informed at all times of the conditions offered to them\(^1\).

In the 1990s –at which time the Act 13/1982, of 7 April, regarding the Social Integration of the Disabled (LISMI) had been in force for several years\(^2\), the association movement broadened its political agenda and included demands such as access to public transport, work adaptations and housing. Again, requests to adapt society’s material structures to the needs of people with disabilities clearly referred to the social model.

According to José Gómez Amate, president of the Association of Spanish Disabled People (AME), this group has to face problems such as: access to buildings, traffic on city roads, use of public transport, job shortages, non-adapted housing and insufficient subsidies\(^3\).

Over this period, the sector’s most pressing demands concerned the removal of obstacles to mobility mainly in urban transport. In this respect, the organisations’ practices were twofold: on the one hand, they offered mobility services by acquiring vans, and on the other, they made demands to adapt public and private transport. People living in rural areas or suburban areas had to resort to van travel services provided by entities in the sector because intercity buses were not adapted and taxi services were very expensive, especially in the case of weekly or monthly trips. This illustrates how the emerging social model coexisted with practices that failed to foster autonomy and societal adaptations to peoples’ needs. In urban environments, buses began to provide access ramps and anchor systems for wheelchairs, though not all of them, leading to discriminatory practices.

The Federation of Physically Disabled Persons of Madrid (FAMMA) claims that 130 out of the 430 low-floor vehicles recently acquired by the EMT do not dispose of access ramps and wheelchair anchors [...] According to a letter from the company, these buses, planned for high demand lines, are designed to facilitate the fast moving of travellers. Wheelchairs would block the passage\(^4\).

This news story, published in 1999, describes a situation of “discrimination” during rush hour. Through discussions with local authorities, the group succeeded in having architectural, urban and transportation barriers removed but further invisible barriers and prejudices were unveiled.

The association movement’s constant demands relating to architectural, urban and transport barriers turned the issue into a political party “programme” priority, leading municipal and autonomous governments to issue regulations aimed at suppressing barriers. In addition, years of persistence by the entities involved brought local authorities to show a greater degree of awareness, not only through regulatory measures but also by including representatives of the association movement in government commissions and bodies on matters relating to accessibility.

Lack of accessibility persisted in intercity buses, trains and airplanes. During the first decade of the 21st century, news items began to reflect transformations in these areas. For example, air transport had to start complying with disabled people’s rights based on European regulations:

Persons with disabilities or reduced mobility must have “the same opportunities to use air transport as other citizens.” To this end, “assistance must be provided to meet their particular needs both at airports and on board using the necessary personnel and...
equipment” and that such assistance “must not involve any additional charges.” That is the purpose of the regulation on the rights of persons with disabilities or reduced mobility in air transport, which will take effect twenty days after its publication in the Official Journal of the European Community\(^5\).

One of the most surprising findings is that news about housing accessibility begins to appear only from 2000 onwards. Surprisingly, the associative movement began by requesting the removal of barriers in public spaces when in fact to make use of them, private spaces – homes where people live– must be accessible first. Many people were “imprisoned” in their own homes because they were not able to leave them.

In Spain, only two out of every ten buildings aimed primarily at housing are accessible to people with some form of physical disability, according to the 2001 housing and population census published by the National Institute of Statistics (\(\text{INE}\)). This national body considers that a home is accessible when a citizen in a wheelchair can reach the interior from the street without assistance. However, to obtain this information, the \(\text{INE}\) only determined whether or not the building had a lift and did not take into account other elements that facilitate the passage for people with reduced mobility (such as ramps, handrails, etc.)\(^6\).

To finish, different news stories appeared that described a new range of communication and accessibility technologies aimed at making life easier by improving accessibility to environments, services, products, etc. Projects designed to offer information on the degree of accessibility of certain environments allows people with disabilities to increase their degree of mobility and personal autonomy. “Universal accessibility” was at this time already being referred to, as reflected in Act 51/2003, of 2 December, on equal opportunities, non-discrimination and universal accessibility for people with disabilities (\(\text{LIONDAU}\)). This political philosophy of universal citizenship is well reflected in the following extract:

We are dedicated to social technology, i.e. technology designed for people, not necessarily for people with functional diversity\(^7\) (Social Technology Foundation).

The issue of architectural, urban and transport barriers is widespread in the Spanish press because it was one of the first issues to be addressed by the sector’s organisations. Three decades later, some progress has obviously been made but the process has not been easy as the dynamic that has characterized this transformation has been as follow: governments legislate, regulations are delayed, the associative movement starts pressurising, some progress occurs, and so on. While people with disabilities have been gaining ground, entities in the sector have been incorporating new demands in their political agendas. This, however, does not imply that older issues have been solved or that discriminatory situations have come to an end.

3.2. From special education to ordinary education

When the Socialist government approved Royal Decree 334/1985 on Special Education, which regulated the inclusion of special education in ordinary primary and secondary schools, the press reacted immediately, arousing a debate on “school integration.” Some of the professionals involved were not in favour of closing special education centres and defended individualised incorporation, i.e. they were against generalised integration by decree.

For María Fernanda Fernández, director of the National Institute of Therapeutic Pedagogy, the concept of integration has been distorted because it has been applied generically to all types of disabled children. This is not feasible. Only some children are really in a condition

\(^5\) “Airlines will have to provide assistance to the disabled at airports” (\(\text{ABC} 18/07/2006\)).
\(^6\) “Only two out of ten residential buildings are accessible for the disabled” (\(\text{ABC} 01/03/2004\)).
\(^7\) “A [Saint James] Way everyone can see” (\(\text{El País} 17/07/2009\)).
to be integrated. Each case should be considered on an individual basis, rather than
generalising disabled children’s integration⁸.

Educational professionals also expressed concern about parents’ attitudes towards the
government’s measures. Some of the most hostile attitudes included the belief that
integrating children with special educational needs had a negative effect on a class’s overall
academic performance.

In 2001, fifteen years after the establishment of the Royal Decree mentioned above and
five years after the RD 696/1995 aimed at students with special educational needs was
approved, discourse towards school integration became more favourable, as illustrated
below:

Going to a conventional school helps the disabled acquire habits and routines, it helps
them mature and progress according to their abilities (Miguel Jerónimo, Director of the
Haíti school) […] Nowadays, integration seems completely natural, but it was initially
widely rejected, especially by the families of non-disabled children, who feared that having
disabled children [in the classroom] was going to lower standards (A spokesman for the
Ministry of Education in Madrid)⁹.

For many professionals, “curricular adaptation is key to these students’ education as it
allows modifying and adjusting didactic and organisational elements providing an
individualised response”¹⁰. This person-centred programme stumbled on a lack of specific
support. The press reported cases of parents going on hunger strikes to obtain a “support
educator” for their children and of families having to address all the local authorities during a
full school year and a half to obtain an educator¹¹. As a result, the issue of necessary human
resources is still under debate today. According to Asunción Domingo, the Director of social
services at FEAPS (the Federation of Organisations for People with Intellectual Disabilities):
“[many families] are very unhappy about the lack of specific support for their children in the
classroom and resort to special education to obtain better care”¹².

Another recurring issue during the period under study was that of training and
awareness of school teachers and staff. According to María Pérez Solís, the representative
of the Spanish Association of School Psychology: “The biggest problem is the transition to
secondary school. Teachers believe they have enough trouble as it is with normal students and
should not have to make additional efforts of integration”¹³.

A new debate thus emerged that divided the educational community. The debate
developed around “special classrooms:”

Integration is very difficult to weave, especially if you want disabled children to actually
learn something useful and not just be parked in a corner rote learning a list of Gothic
kings. To prevent this, teachers, working with tutors and school counsellors, must define
curricular adaptations on an individual basis. When adaptation is deemed to be unfeasible,
they should leave the classroom and receive specific classes, although they should remain
as integrated as possible in subjects such as music, gymnastics or the visual arts¹⁴.

We found a story in year 2012 of civil disobedience in a discriminatory situation. The Court
of Instruction number 1 of Palencia charged the parents of an 8-year-old autistic child for an
alleged offence of family neglect because they refused to take their child to a special education

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8 “Disabled children will be integrated, by decree, into the educational system” (ABC 5/02/1985).
9 “Some very special children” (El País 4/06/2001).
10 “Special Needs Education in Spain” (ABC 8/10/2002).
11 “The disabled and professionals reject «isolated» teaching” (El País 5/04/2010).
12 “Some very special children” (El País 5/04/2010).
14 “Some very special children” (El País 4/06/2001).
school. They claimed their child should be schooled in an ordinary school. These decisions are today left to public guidance services provided by autonomous communities. After undergoing psycho-pedagogical evaluation, these guidance services decide whether or not children can study at an integration school.

Despite the passage of time, the educational model has not been consolidated. Many problems persist around the definition of a policy committed to educational inclusion. “Should true pedagogical innovation not consist in inclusive experiences, in ways to respond to the needs of all students in the classroom, without having to take students out, without letting them study on the side?” (García, 2012, p. 96).

3.3. Ordinary employment and sheltered employment

A memorandum submitted in 1986 by the Commission of the European Communities to the EEC Council of Ministers stated that “the problem of employment and unemployment of disabled people is very complex. [...] The Commission considers it essential to give greater importance to the capacity of the disabled and to stress that even the most serious handicaps are a limited set of handicaps”.

According to the recommendations of this Commission, member countries should establish recruitment quotas in public and private companies.

These quotas were already defined in the LISMI (1982) but the European Commission report covered a wider range of measures beyond quotas. An analysis of the news reveals a continuous debate mainly on the lack of enforcement of the 2% quota in private employment and the 3% quota in public employment. On the one hand, integration quotas in ordinary jobs were not being met. It is noteworthy that companies with over 50 employees do not prevail in Spain. The majority are small and medium companies, and they usually employ less than 50 employees.

Acknowledging that the 2% quota had not been sufficiently implemented, alternative measures and control mechanisms were established. This need was made public for the first time in 1997 when a specific scheme was approved to foster the employment of persons with disabilities, including a series of urgent implementation measures. But it was not until year 2000, with the RD 27/2000 of 14 January, establishing alternative measures of an exceptional nature to comply with the reserve quota of 2% for disabled workers in enterprises of 50 or more workers, that companies having to meet the 2% quota could start to implement alternative measures.

These measures were extended by work enclave regulations. The RD 290/2004, of 20th February, regulating work enclaves as a measure to foster the employment of people with disabilities aimed, among other objectives, at making it easier for companies to fulfil the legal reserve quota of 2%. Work enclaves can be described as work or service subcontractors, between special employment centres and ordinary companies. They aim at facilitating the transition from sheltered employment to ordinary employment.

In relation to sheltered employment, LISMI (1982) defines Special Employment Centres as those that participate regularly in market operations had are mainly aimed, in addition to performing productive work, at ensuring paid employment and provision of services for the personal and social adjustment of workers with disabilities, while seeking a means of integrating the greatest number of them into normal work regimes in ordinary enterprises. According to KPMG’s report on special employment centres (2011, p. 4-5), the creation of these centres followed the four key steps below:

1. In 1982 the LISMI 13/1982 was published. It defined special employment centres for the first time.

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15 “Accused of failing to school their autistic child” (ABC 5/01/2012).
2. The number of centres slightly increased between 1986 and 1987, possibly due to the publication of two Royal Decrees, 2273/1985 and 1368/1985, that implemented the legislation on special employment centres.

3. Around 1998, an Order by the Ministry of Work and Social Affairs was published establishing the regulatory basis for the granting of public aids and subsidies aimed at the work integration of people with disabilities. This may explain the rise in special employment centres over the following decade.

4. The fourth step took place in year 2000 and could be due to the publication of Royal Decree 27/2000, which established alternative measures of an exceptional nature to comply with the 2% reserve quota in favour of disabled workers in companies with over 50 employees.

We found a recurring idea relating to employment that was shared by different social actors: employment was the main route to social integration. This discourse links social participation to the axis of production and consumption, that is, it reinforces the idea that productive capacity is decisive for social inclusion. For his part, Díaz (2010) argues that people with disabilities are excluded from other life dimensions beyond production and consumption, i.e. political participation, culture, leisure, social relations, sexuality, etc.

3.4. From sport as rehabilitation to sport as recreation

After World War II, especially at the Stoke-Mandeville Hospital near London, Dr Ludwig Guttman introduced sport as a means of rehabilitating war cripples. What initially started off as rehabilitation gradually became more recreational, to later turn into a competitive exercise. Coinciding with the 1948 London Olympic Games, Ludwig organised the first “special” games for paraplegics at his hospital. In 1960, the International Organisation of Sports for the Disabled (ISOD) was established, which set international standards for the competition. The “Paralympic” Olympics were thus launched – from then on at the same date as the Olympics.

Spain participated for the first time in the Paralympic Games in 1988, in Seoul. On 22 September 1989, the International Paralympic Committee was officially set up in Düsseldorf, Germany, as a non-profit organisation. The Olympic Games in Barcelona in 1992 boosted high competition sport for people with disabilities in Spain. This event triggered frequent news on the topic over the period under study.

This integration model is based on “competitiveness.” For many, top-level sport is a way of attaining a valued social role, a change of life, a means to travel, know people, overcome problems, gain self-esteem, be successful, work, etc. According to Santiago Sanz:

I live by and for training. My dream is to have many more years as an athlete. Sport is how I earn a living. A normal day is a day of sports, training in the morning and in the afternoon, and travelling from one place to another. I am privileged. This started as a hobby and now it’s my job.

Biographies of these top-level athletes are exposed in the press as examples of individual achievement:

The more things require effort, the more you value them. That teaches the Paralympic spirit. A life story full of difficulties that had to be overcome lies behind each medal and each participation. We start at a critical stage and set up mechanisms of improvement to achieve positive outcomes (Gema Hassen-Bey, fencing female athlete).

This model of integration is not without difficulties. First, not all athletes fulfil their aspirations of success and these “other stories” are not reported in the press. Possible trauma after defeat, for example, may constitute a very painful process. Second, many athletes are
more affected by funding problems than training problems, a continuing sign of the discrimination these people have to face. For Gema Hassen-Bey, a female fencing athlete:

Lack of financial support adds to our physical difficulties. The Paralympics programme does not yet have an ADO plan. Getting to the Paralympic Games takes four years of intense preparation with the help of top technicians and attending international competitions. That is why gaining the support of private companies who can benefit from our image of achievement is essential—and it is still insufficient.

We will now approach sport from a wider perspective, i.e. leisure. Stories relating to sport have been told until now adopting an “exotelic” perspective, that is to say, understanding sport as a means to an end such as success, recognition, being accepted, etc. Yet sport also has an “autotelic” dimension, that is, it can be an end in itself as it leads to the enjoyment of sociable and fun moments.

News began to appear in the 1990s referring to a more playful aspect of sport that overshadowed the competitive dimension of top-level sport. Stories can be found in the press on so-called “adapted” sports. The También Foundation has been dedicated to the social integration of people with disabilities through adapted sport since 2001, so they can spend their free time in a normal way, providing the necessary material, logistics and subsidies to cover costs.

They [the También Foundation] understand sport as a means of building self-esteem and self-improvement rather than personal success. [...] We want disabled people to realise that they can continue to do things. [...] To be integrated into the world of work, you have to have courage and be self-confident. This is why going out there and trying things out is important, people should live with their disability in the most normal possible way.

Sport, having originated in a rehabilitation approach, thus adopted a more social turn.

3.5. From internment to independent living

With the advent of democracy, reforms and changes to the structure of local authorities would be dominated by the medical-rehabilitation model rationale. The priority was to place those with the greatest needs in centres.

The centre for the physically handicapped, which belongs to the National Institute of Social Services (INSERSO), was setup in 1985, but has not yet been fully operational. The residence, located on Montánchez road, is structured into independent modules and single rooms, where it welcomes physically disabled people with serious conditions, mostly incurable cases.

Confinement and concealment had become commonplace in the history of care for people with disabilities. They were the fruit of the marginalisation model that prevailed in past times, in which people were cared for by charitable and benevolent entities. In this way, internment became natural in our society, to the point that the residential model constituted the most widespread and indisputable response from the government, entities in the sector and families themselves. Contributions from foundations, savings banks, municipalities, etc., consolidated this formula.

In year 2000, institutionalisation was an obvious and natural fact, but the debate that then arose focused on the centres’ funding model. Entities in the sector having shown a decisive commitment to the residential model had different views on how to sustain them.

The Council of Representatives of Handicapped Persons (CERMI), made up of associations of disabled people in Madrid, decided to oppose the regional government’s proposal to

20 “Our prize is a smile, not a medal” (ABC 14/04/2008).
21 “The Queen” (ABC 15/04/1986).
take family income into account. Its chairwoman, María Luisa Ramón-Laca, adopted this opposing stance at the CERMI meeting held on Wednesday with the heads of Social Services. Surprisingly, an agreement was reached whereby the CERMI “unanimously” expressed its “agreement to establish the per capita income of the coexistence unit as a criterion for setting public prices of residences and day centres instead of a percentage of disabled people’s state pensions”22.

The naturalisation of the residential model began to be questioned in the mid-90s, when the subject of housing access emerged from the persistent struggles of sector entities to eliminate building and urban barriers. While the residential model was being defended, demands for access to adapted housing were also being made, albeit intermittently. This latter issue shed light on the group’s difficulties in living in autonomous, independent and egalitarian conditions. Some of the entities that set up and managed residences were looking for alternative models through housing. Again, signs of the social model were appearing, suggesting that the model was emerging in this domain.

The Coordinator of the Physically Disabled of the Autonomous Community has taken steps to build various residential homes designed for the physically disabled (…) The aim is to construct a building with four types of housing units, including one to four bedrooms, with constructed areas covering a surface area of 77 to 129 square meters. The ground floor will be dedicated to different services such as a restaurant, cafeteria, a laundry room, a gymnasium with a rehabilitation area, a parking space, a day centre and a residential area. There will be no architectural barriers in the design23.

At the time, it was possible to view this initiative as welcome news and a good idea, but the model is now rejected by members of the Independent Living Movement because it includes features proper to the medical model.

In a context of transfer of powers to the Autonomous Communities, the Basque Country took the lead in implementing programmes facilitating independent living.

Until recently, these people were forced to live in a residence or depend on their families for most of the day. Now, with the regional programme, they receive a grant of 10,000 euros a year from the local council, which allows them to “live in their homes and organise their own care network,” says Esther Larrañaga, the Social Policy deputy. This contribution is compatible with other types of public resources, such as subsidies for technical support, home care service or a place in a day centre24.

The firmest and clearest discourse against institutionalisation can be found in the formulation and application of Act 39/2006 to promote personal autonomy and care for people in situations of dependency. This act is another relevant piece of legislation in the area of disability, passed as a result of the progressive ageing of the Spanish population and, consequently, the increase in situations of dependence that this can generate. It combines both paradigms, but with a clear tendency towards the rehabilitation paradigm over the social paradigm, on account of the characteristics and access to services and provisions set out by this law. The most critical voices were heard during the 2001 Independent Living Forum, which launched a narrative in favour of independent living, calling for the figure of “personal assistant.”

This act does not offer us the means we need (that belong to us by right) to live with equal opportunities in our environment, with family and friends; on the contrary, services will predominate (it is said that up to 80,000 residential places will be provided in which to “lock us in”). The consensus among government, employers and unions is more than dubious and clearly indicative of the distribution of the dependency “pie,” through the

22 “Ruiz-Gallardón, booed in the Assembly by some 60 relatives of disabled people” (El País 15/12/2000).
23 “Proposal of residential housing construction for the physically handicapped” (ABC 24/08/1996).
construction and private management of centres and services. Care for dependent people doesn’t seem to matter at all, except as a means for some people to do business and who will make us pay for services we do not like, that we are not satisfied with, and that do not correspond to the services we have the right to receive.25

The Independent Living Forum played a major role, seizing the opportunity to influence the Act, and apply the principles of the social model. To achieve an independent life, it is not only necessary to emancipate oneself from the family home, but also to have access to a personal assistant who is able to provide the attention and care traditionally carried out by family members –particularly women.

Last May, Héctor gained autonomy. The PIUNE programme of the Autonomous Solidarity Foundation (FAS) assigned him a personal assistant. He is not the only student to benefit from the help of this figure. Six other boys and girls with serious disabilities in the Autonomous Foundation now benefit from this service.26

The support that certain Foundations provided in the 80s to build residential centres has now turned into aid to foster personal autonomy. These types of programmes and the recognition of the figure of personal assistant in Act 39/2006 aimed at fostering personal autonomy and care for people in a situation of dependency both indicate that Spain is set to opens its doors to de-institutionalisation over the current decade.

4. Conclusions-Discussion

Spanish press discourse seems to have kept in line with the evolution of disability policies. The news we analysed started at the time of Spain’s democratisation, which set in motion the restructuring of governmental services and local authorities. Discourses and practices in step with the paradigm of personal autonomy gained ground during the first decade of the 21st century, protected by the international Convention on the Rights of Persons with Disabilities. It is, however, necessary to analyse specific domains of implementation to determine the actual underlying paradigms.

The issue of accessibility is directly related to the personal autonomy paradigm, insofar as changing the environment promotes the autonomy of people with disabilities and their participation in society. Discourses and practices around this issue have coincided: different actors have been claiming and/or been legislating to make environments accessible. Although great progress has been made in removing physical barriers, major efforts are still necessary to eliminate intangible barriers, as prejudices and stereotypes generate discriminatory and oppressive attitudes.

Contradictory practices and discourses can be found in the field of education, so we can consider that the educational model is not yet consolidated. Although different regulatory measures provide orientations that are inclusive in spirit, they always leave the door open to schooling in special education centres.

In the domain of employment, positive discrimination measures, job adaptations, and valuation of skills can be associated with a social perspective rather than a medical one. In the model where education–employment–integration are interrelated, the social phenomenon of disability still retains a rehabilitation undertone. The “burden of proof” concept is reflected in many news items, in other words, when people with disabilities are offered a job, they have to prove they can do it better than anyone else and that they can take on as many “normal” functions as possible in the best possible way. Meanwhile, the model further segregates people who are not able to produce at the required pace.

In the domain of sport, although practices originally followed the rehabilitation paradigm, medical conceptions now exist alongside social conceptions according to the

26 “I can now direct my life” (El País 11 02 2008)
intervention area. A “segregated” model of integration can be found because of the competitive logic of peer equality and specific institutional sport organisations and schools for people with identical or similar disabilities. This means that in a world of competitive sport, individual capabilities also structure accessibility and participation opportunities, just as they do in schools –concerning the ability to assimilate knowledge –and workplaces –in terms of the capacity to produce economic value.

The denaturalisation of the residential model, due to practices based on independent living in the community, is a good illustration of how the rehabilitation paradigm has evolved towards the personal autonomy paradigm. But in reality, there is evidence that both paradigms coexist in discourses and practices. Residential centres continue to open while personal assistance projects are fostered.

Our discourse analysis of the press illustrated a transition from the rehabilitation paradigm to the personal autonomy paradigm. The Independent Living movement has added new fields of intervention –access to housing, personal assistants, deinstitutionalisation– to the traditional areas of education and work inclusion, architectural barriers and accessibility, leisure and tourism, etc., which are also reflected in the press. Extensive news publication in the coming years will give rise to possible updated discourse analyses.

References


