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EXPLORING HUMAN DIVERSITY: A DOSSIER DEVOTED TO DISABILITY HISTORY / EXPLORANDO LA DIVERSIDAD HUMANA: UN DOSSIER DEDICADO A LA HISTORIA DE LA DISCAPACIDAD

# FROM RESIGNATION TO NON-CONFORMISM: ASSOCIATION MOVEMENT, FAMILY AND INTELLECTUAL DISABILITY IN FRANCO'S SPAIN (1957-1975)

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ABSTRACT: The association movement related to intellectual disability started in Spain during the second part of Franco's dictatorship. Its appearance was rather late with respect to other countries, where associations of families and defenders of people with intellectual disabilities had been going on for some time and were forming larger groups, first European-wide then internationally. Spanish parents were the principal actor of this social movement. They demanded the right of their children to receive a decent education and to have a more secure future beyond that of childhood. From 1959 (the year that first association —ASPRONA— was created in Valencia) until the end of the Franco's regime more than one hundred family associations were created all over the country. Additionally, in 1964, the Spanish Federation of Societies for the Protection of the Subnormal (FEAPS) was created to liaise with the public administration and be in charge of promoting and helping the other associations. By analysing as main sources bulletins and reports published by these disability organisations, this article explains the rise of parents' activism, it describes the spread of the self-organised groups and it looks at the way in which these associations built their identities and performed their intended functions. The paper focuses also on the criticisms and problems these groups faced and on the process that led them to take a more confrontational stance.

**KEY WORDS**: Association movement; Intellectual disability; Family; Franco's Spain.

## DE LA RESIGNACIÓN AL INCONFORMISMO: MOVIMIENTO ASOCIATIVO, FAMILIA Y DISCAPACIDAD INTE-LECTUAL EN LA ESPAÑA DE FRANCO (1957-1975)

**RESUMEN:** El movimiento asociativo relacionado con la discapacidad intelectual comenzó en España durante la segunda parte de la dictadura Franquista. Su aparición fue relativamente tardía respecto a otros países, donde asociaciones de familias y defensores de las personas con discapacidad intelectual llevaban funcionando algún tiempo y estaban comenzado a formar grupos más grandes, primero a nivel europeo y posteriormente a nivel internacional. Los padres españoles fueron los actores principales de este movimiento social. Ellos reclamaron el derecho de sus hijos a recibir una educación adecuada y a tener un futuro más seguro en su etapa adulta. Desde 1959 (el año en que se creaba la primera asociación —ASPRONA— en Valencia) hasta el final del régimen de Franco se crearon más de un centenar de asociaciones familiares en el territorio nacional. Además, en 1964, se creaba la Federación Española de Asociaciones pro Subnormales (FEAPS) con el objeto de cooperar con la administración pública y encargarse de promover la creación de otras agrupaciones y contribuir a su desarrollo. Utilizando como fuentes principales los boletines e informes publicados por estas asociaciones, este artículo explica la aparición del activismo de los padres, describe la extensión de estos grupos y revisa el modo en que las asociaciones construyeron sus identidades y llevaron a cabo las funciones que se plantearon. El artículo analiza también las críticas y los problemas a los que estos grupos tuvieron que enfrentarse y el proceso que les condujo a asumir un discurso más beligerante al finalizar la dictadura.

PALABRAS CLAVE: Movimiento asociativo; Discapacidad intelectual; Familia; Franquismo.

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## **INTRODUCTION**

In 1970, in a book entitled Mental Deficiency. An Urgent Matter, the physician and father of an intellectually disabled girl, Luis de Azúa, recounted how the indifference, or even worse, the rejection with which intellectually disabled people had always been considered by Spanish society were being replaced by awareness and recognition. He also stated that this shift in ideas and attitudes was connected to a change in the families themselves: "The families and friends of intellectually disabled people have changed and we have moved on from resignation to non-conformism. We are not satisfied with letting our children vegetate, languidly in many cases or in even worse conditions in many others" (De Azúa, 1970, p. 103). Motivated by these new feelings, Spanish parents decided to come together and create self-organised groups aimed at fighting for their children's well-being.

As we will explain later, this family movement, talked about by Luis de Azúa, was part of a widespread phenomenon. From the thirties onwards, voluntary associations formed by parents of intellectually disabled people were playing a key role in getting the question of intellectual disability onto social and political agendas all over the world. The interest in studying the emergence of these groups has been growing in recent years. Some authors have analysed this issue within the context of the emergence of the association movement of disabled people in general, like Barral's article on France (2007) and Scianchi's one on Italy (2014). Other works have been devoted to study this phenomenon in a more monographic way, focusing on intellectual disability in Australia (Earl, 2011) and, specially, in USA (Dybwad, 1990; Jones, 2004; Castles, 2004; Carey, 2009). There are few studies on the self-organised Spanish groups, and they mainly describe the history of local or regional associations (Molina, 2008; Alvarez Urricelqui, 2009; Alvarez Solis, 2012; Espinosa, 2012). The only exceptions have been a monographic study on the history of the National Federation (López Iglesias, 2014) and a book's chapter where the author briefly examines the first steps of this movement within the framework of the disability protest movement (Bregain, 2013b).

In this paper, we want to offer a more comprehensive view of the family movement during Franco's dictatorship. By analysing as main sources bulletins and reports published by these disability organisations, we will first contextualise the rise of parents' activism. Then we will describe the spread of the self-organised groups. Next, we will look at the way in which these associations built

their identities and performed their intended functions. Finally, we will focus on the criticisms and problems these groups faced and on the process that led them to take a more confrontational stance.

#### 1. THE RISE OF PARENTS' ACTIVISM

People with intellectual disability became a concern for Spanish society at the beginning of the twentieth century. Repeating ideas that were circulating internationally and that invoked humanitarian, economic and social protection reasons, some professional groups started defending the advisability of segregating these people in special institutions that could offer them the medical and educational treatment that their condition required. During the first decades of that century, the first institutions intended to take care of the intellectually disabled persons were created in Spain (Del Cura, 2011). The lack of any budget for the few public centres, the high cost of private centres and the reduced capacity of the installations that characterised all of them, prevented these developments from affecting the lives of most of these people and their families.

The advent of the dictatorship in 1939 did not make this situation any better. In the aftermath of the Civil War, several institutions founded in the previous period were closed and their professional staff exiled or removed in ideological purges. Others, although they managed to survive the war and the reorganisations imposed by the new government, needed a large economic investment that was difficult to tackle in an impoverished Spain that was being pushed towards self-sufficiency (Richards, 1998). In addition, the dictatorship had little interest in intellectual disability when defining the social policies on disability for these first years (Martínez-Pérez and Del Cura, 2015)2. Intellectually disabled people did not fit well in the stereotype of productive, healthy citizens that the dictatorship wanted for the New Spain that was being built. Unlike other persons with physical or sensorial impairments, people with intellectual deficiencies were seen as unable to contribute to the common goal of increasing production and the economic prosperity of the nation. These circumstances made them a deeply marginalised collective at that time.

Ernesto Puerto —father of an intellectually disabled child and one of the pioneers of the associative movement—, explained some years later that:

The idea of trying to take a disabled school-age child to a school where a suitable education could be provided, was little more than an insult to society and a legal violation by any teacher that accepted the child in class, since the ministerial inspections forbade these children to mix with those considered to be 'normal' children at school. In addition to any problems of a moral nature, there was a fear of possible "contagion".<sup>3</sup>

The only alternative parents had was to send their children to one of the few existing specialised centres, but the very few places and, above all, the cost of these institutions forced most of the families to deal with the problem privately. The majority of the intellectually disabled persons were confined to their houses or neglected in long-stay institutions or charitable asylums; remaining invisible to society and the State. However, this lack of suitable services was not the only reason for the invisibility of intellectually disabled people. At that time, parents felt isolated and socially rejected. They usually kept the problem hidden like a guilty secret, seeing it as a punishment or a trial sent by God that they should face with resignation and in silence:

We walked with our children —Ernesto Puerto recounted in the same interview— through the city streets fearfully and self-consciously, seeing how people stopped beside us and stared at us, pointing at our child as if to make us responsible for his misfortune. They were children of sin, of vice, of the corruption of our behaviour.<sup>4</sup>

The opening up of the Dictatorship, at the beginning of the 1950s, had an impact on the field of disability. The end of the international isolation provided the regime with much needed financial resources and enabled it to participate in various international organisations such as the United Nations or the World Health Organisation (Pardo, 2008). The new situation permitted the entry of news and information on intellectual disability (via publications or specialised advisers) and allowed Spanish experts to travel abroad and to find out how other countries deal with the situation (Ballester, 2012). Driven by the international ideas and taking advantage of the economic relief, the government started to create several boards and care services (Del Cura, 2016). However, these measures —insufficient and poorly funded— had very little impact on the life of intellectually disabled people.

By the end of the 1950's, families were disappointed and angered by the barriers existing against receiving the treatment and education their children needed. Moreover, they felt frustrated because State's effort was mainly addressed at helping people with physical impairments. As we have previously mentioned, at that point, parents decided to change the way they

were facing the problem and to bring it out into the open. In order to make up for the lost time, they decided to travel abroad to gain knowledge from "other people's experience" and to adapt "the tried and tested methods and systems" of other countries to Spain (Raventós, 1964, p. 309). Thus, some parents and, occasionally, experts travelled abroad to see and experience these methods first-hand, to study the legislation, and to contact doctors, pedagogues, heads of centres and, especially, other parents belonging to some of the self-organised groups that had grown up abroad (Borreguero and Ferrero, 1964).

During the thirties and forties, local groups (which were later to take on a national role), appeared in the United States, France, New Zealand and Great Britain. By the end of the forties, the first National Association in Great Britain was set up, the National Society for Mentally Handicapped Children for England and Wales, and in 1950 the National Association for Retarded Children was created in the USA. From the mid-fifties onwards, associations sprung up around the world and by the late sixties there were associations in more than 60 countries and there were around 28 national associations. Additionally, in 1959 the first step towards the creation of a formal international organisation was taken. Three leaders of the movement in Holland, Great Britain and Germany met to plan for a European League of Societies, and as a result, the League was founded in 1960. Two years later, the decision was taken to open membership to all parents and other national organisations working in any part of the world, so creating the International League (Dybwad, 1966; Boggs, 1963). These voluntary organisations started from the same beginnings, working in the same uncultivated field. Everywhere intellectually disabled people were not considered, there was no knowledge about their problem, no official provisions and no public understanding. Frequently, the only solution found for the situation was segregation. For this reason, although there were differences between these groups, regarding the different socio-political contexts in which they arose, they all coincided both in the goals they were pursuing and in the way to reach them (International League of Societies for the Mentally Handicapped, 1967).

As we have previously said, Spanish parents contacted with these foreign experiences and in doing so they met new conceptions on intellectual disability, they felt their feelings legitimated and they got inspired to organise their own parent-sponsored associations.

## 2. THE SPREAD OF SELF-ORGANISED PARENT'S GROUPS

Some of these Spanish parents came from the city of Valencia. They were part of a group of fathers and mothers that —sharing similar problems and the wish to get their children a better future— began to meet regularly in the mid-fifties. In 1957, this group of parents decided to ask for government authorisation to found an association. As soon as they did it, they were placed under suspicion. In Franco's Spain, political parties were forbidden (with the exception of the official one) and all associations were fiercely monitored. Dictatorship judged the associative movement as a source of instability, therefore the few groups permitted, apart from those belonging to the Catholic Church and the National Movement<sup>5</sup>, were obliged to prove they had no political agenda (Sánchez, 2005; Maza, 2008).

As Ernesto Puerto (the first president of the association) related in the interview he gave in the mid-1980s, the parents of Valencia suffered a government inquiry. Their proposal had to be revised and accepted both by the General Authorities for health, education and public order and by the Church. Moreover, the police visited their houses during the night demanding to know their political background and they were also obliged to appear before a judge to explain their intentions.<sup>6</sup>

They needed two years to get a final approval. In 1959, the first Spanish self-organised parent's group, the Association for Abnormal Children (with the acronym ASPRONA) was set up in Valencia. One year later, activists from Valencia made contact with other parents who had established a second group in San Sebastian. In 1961 both associations sent some members outside Spain to attend a conference organised by the European League of Societies for the Mentally Handicapped in London, and to visit education and care centres, adults' homes, and sheltered workshops in England and Holland (Puerto, 2014, p.16). On their return, ASPRONA representatives sent an open letter to several national and local newspapers to get their association known and to encourage other parents of intellectually disabled children to follow suit.

Their call was successful. By 1963, there were more than 15 associations dotted around the country. These groups inspired the *First Technical Conference on the Subnormal Children's problem*. A meeting organised in Madrid by the National Delegation of Associations, which brought together experts, government representatives and parents. During the

conference, the young associative movement was discussed, and parents were encouraged to found new provincial groups, incorporating experts and public workers as advisors (Suárez and Buceta, 1964). Additionally, the creation of a national federation was recommended as an intermediary with the central government (Puerto, 1964). Just one year after the conference, in 1964, the *Spanish Federation of Associations for Subnormal Children* (known as FEAPS)<sup>8</sup> was created, gathering together 20 associations and 7480 members. The FEAPS' role was to promote and guide the regional groups, to connect them with the public administration, to organise informative actions (conferences, meetings...) and to promote research on intellectual disability.

One of the FEAPS' first actions was to continue the campaign that ASPRONA had started. It was necessary to persuade the families of the importance of joining together and the rest of the society of the value to become "supporter members" (Raventós, 1964). This new call coincided with the passing of a Law of Associations9 that in turn, responded to an increasingly tolerant attitude by the dictatorship towards social participation movements, whenever, obviously, these movements had no political inclinations, or concealed an ideology that opposed the regime (Radcliff, 2009). In this new scenario, parents' organisations began to spring up around the country and, by the end of the dictatorship —in 1975— there were around 110 (local or provincial) groups. The highest number of associations was along the east coast —Valencia (4), Alicante (4), and especially Barcelona (13)—, and only one province (Guadalajara) had none at all.

## 3. THE PARENT AGENDA

In creating the associations, Spanish parents wanted —like parents abroad— to provide both a source of mutual aid and comfort and a basis for direct action to obtain better education and opportunities for their children. They wanted to identify the problems both they and their children had to face and to get the State to provide real solutions. From a practical point of view, their main goals were to promote the training of specialised staff and to encourage the setting up of care and rehabilitation centres, schools, professional training centres and sheltered workshops. The direct participation of these associations in the creation of the aforementioned services was optional, but not recommended due to the economic and organisational difficulties the management entailed (De Azúa, 1970; Pérez Marín, 1968).

However, parents were more ambitious; they aspired to developing a better understanding of their children's condition by the public, experts and the government and to bringing about a social change that would result in the widespread acknowledgement of the right to social integration for intellectually disabled people. They wanted to transform families, mobilising them and eradicating attitudes of shame and fear via pro-active guidance. Moreover, they hoped to change the social image of their children and themselves, doing away with the attitudes of rejection and compassion found in society; destroying the idea of un-recoverability (which was particularly associated with the more severe cases); and wiping out the unfair relationship between recovery and economic return that both the State and the society expected to obtain. Although the potential productivity of their children was one of the main reasons used, at that moment, to justify access to services and rights, parents wanted to ensure that every child, regardless of his or her productivity or level of adjustment, received services.

#### 3.1. "Subnormal" as a banner

Very early on, the parents understood that it was necessary to choose a common term that was going to be used to identify their struggle and to differentiate their children from other groups of disabled people (De Azúa, 1969). They did not want to employ the labels used to refer their children at that time, especially the most common term "abnormal", because they considered it pejorative and stigmatising (García, 1958). As Luis de Azúa (the head of the FEAPS in the seventies) stated in 1970, they wanted to find a neutral word that they could use as a "banner to raise public awareness" (De Azúa, 1970, p. 106).

Parents found this word in the first technical report on intellectual disability published by the World Health Organisation in 1954 (WHO, 1954). In this report, the expressions "mentally subnormal" and "mental subnormality" were used respectively, to refer to the people affected and the impairment itself. From the creation of the Federation, parents used the term "subnormal" (generally as a noun) for referring to their children, and included the word in their associations' name and the activities and services they were providing (Arbelo, 1968; De Azua, 1970). The term was also well received by the civil servants and the experts and became habitual in media and daily life; although in technical documents, the expressions "oligophrenia" and "mental deficiency" were used too.

Once their banner had been selected, the associations fought to keep it and to avoid any confusion caused by the misuse that some professionals, the media and, above all, the government made of the term. In news items, articles and legislation from the time the word "subnormal" was used to indicate disabled people in general, a point that for different reasons upset all the groups of disabled people. Those with intellectual impairments (or their representatives) because they did not want to lose the identity that they were building up, and other groups because they did not want to be identified with an impairment that involved greater stigmatisation and marginalisation (Sierra, 1968).

Towards the end of the dictatorship, voices began to rise which, whilst admitting the success and usefulness that the term had had in the past, indicated the disadvantages of a label that contributed towards consolidating a marginalising social element and "that petrified and froze certain individuals in an irrevocable category".<sup>11</sup> For this reason, they proposed a change in the terminology that ensured the discontinuation of use of a word that had also started acquiring negative connotations in everyday language and was becoming more and more rejected by people with intellectual disabilities and their families.<sup>12</sup>

#### 3.2. Associations in action

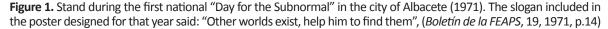
In order to achieve their aims, the associations undertook a wide range of activities. As we mentioned previously, creating direct services was not the aim of all of them; although it is true that some parents organised themselves with the sole purpose of creating centres for their children, others defended the fact that their role was that of vindicating these services and not that of providing them (Sánchez Llamosas, 1972). However, the lack of a rapid and resolute response by the authorities obliged the associations, sooner or later, to become suppliers of direct services. By the end of the dictatorship, they had set up care centres for severely intellectually disabled people, school centres, professional training centres, sheltered workshops, leisure clubs and summer camps. The fact that the organisations finally had to take on this role directly benefitted the people who they wanted to protect but, at the same time, it also had a negative effect because it slowed down the actions carried out by the State. Franco's authorities settled down and decided that the associations were the solution (at least, the immediate solution) to the problem regarding intellectual disability.

Other actions by these groups of parents were aimed at establishing a dialogue with the local and national authorities and to take part, via the National Federation, in organisations, boards and public commissions involved in protecting, caring for and educating intellectually disabled people. Moreover, they collaborated in the organisation of new national conferences on intellectual disability, <sup>13</sup> and they attended the international conferences organised by the International League of Societies for the Mentally Handicapped (to which FEAPS had belonged since its creation) and by the International Catholic Child Bureau (Jordana de Pozas, 1984).

Furthermore, they undertook the task of training and informing the families, organising courses, providing them with information about centres and grants, and helping them apply for subsidies, allowances and other state benefits. They also provided information on the work of the associations via summaries and bulletins. Finally, they supplied information on how to understand and manage intellectual disability to parents and professionals by having speakers who had expert knowledge in some relevant area and through printed material that included newsletters, brochures and monthly journals. Probably the most representative publications of the associative movement's narrative were those published by the Federation (they both

are currently still being published): the quarterly journal *Boletín de la FEAPS (FEAPS' Bulletin*), later on called *Siglo Cero (Zero Century)*; and the monthly, free leaflet *Voces de la FEAPS (FEAPS' Voices)*. The first one was more technical and specialised and the second one was more journalistic, accessible and open to readers' opinions. Both publications held a critical posture, which increased towards the end of the dictatorship, regarding the situation of the intellectually disabled, the supposed achievements of Franco's government and the actions carried out by the associations themselves.

Lastly, the associations carried out the important job of spreading propaganda. They ran campaigns aimed at raising awareness of the problem and fund-raising. They organised festivals, awarded prizes to press articles and children's stories, and used the press, radio and television to publicise the conferences, the setting up of new specialised centres, or the passing of local or national measures. All this propaganda came together with the founding of the "Day for the Subnormal" on April 26th (the day FEAPS was founded). This campaign started on a local or provincial scale, but which by 1971 had become national, with the FEAPS coordinating the different actions. During the aforementioned day, the associations raised funds and gained publicity via posters, leaflets, advertisements and stands in the street (Figure 1).



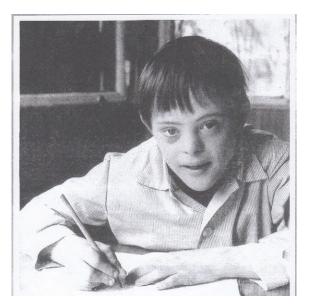


Following an idea used by associations for the disabled abroad, the Spanish groups chose the image of an innocent child to bring the whole problem into the public eye. They also chose a positive message that focused on what this child was able to do instead of what he could not do. The slogans used for the campaign spoke about children who deserved people's love and help, and who were able, once given the opportunity, to contribute to society<sup>14</sup>. By portraying disabled people as children, Spanish parents attempted, in the same way that foreign parents were doing (Carey, 2009), to extend the demand for care to their entire lives. In 1972, the leaflet *Voces* explained the image chosen for the campaign (**Figure 2**) in this way:

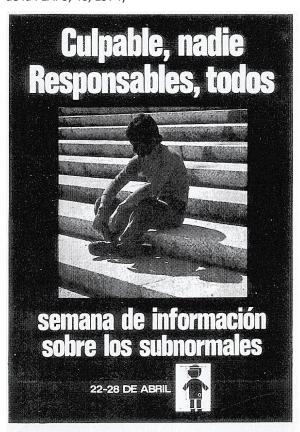
A white page, a notebook and a life ahead of him that could be beautiful. Our friend, as many others, has only just started out. He needs help for the long journey; special education, the learning of a trade, the finding of a job, perhaps guardianship and a home for when his parents are no longer with him. This is the "message" given by this year's campaign (Abad, 1972, n. p.).

The focus began to change at the end of the dictatorship. In 1974, when the Day for the Subnormal became a whole *Week of Information about the Subnormal People*, the children's picture was replaced with the image of an isolated young person and the friendly message turned into a wakeup call to a society that was also responsible for the marginalisation that intellectually disabled people had to face (Figure 3).

**Figure 2**. Fragment of the poster used in 1972, which used the slogan "Help me to go on" (*Boletín de la Feaps*, 21, 1972, cover)



**Figure 3**. Poster for the campaign in 1974 with the slogan: "Guilty, nobody; responsible, everybody" (*Voces de la FEAPS*, 40, 1974)



## 4. FACING PROBLEMS AND CRITICS

Despite their work, the associations came up against fierce criticism and many problems right from the start. In 1968, the director of the FEAPS' magazine wrote in one its editorials:

The Pro Subnormal Associations are today fighting bloodless battles against society, against the government, against the affected parents themselves and against their members. There so many "enemies" to face and so much ground to conquer, that all the aggressiveness of the associations and their leaders is not enough at this time (Perez Marín, 1968, p. 6).

The starting point of these problems was related to the nature of the associations themselves and the way in which they had been organised (Bittini, 1973). From its creation, groups faced difficulties to find experienced leaders, able to represent the associations and to fight for the general interest. They were unable to reach a productive coordination between the associations and FEAPS. In ad-

dition, they could not convince families to get involved in their adventure. Membership levels were very low, compared to affected families (between 7% and 8%), and it was very frequent for associates to leave the associations (especially amongst older members) either because they had solved their children's problems or because they thought that they got little out of association. Moreover, the level of information and/or training of the families was minimal; most parents did not read material related to their children's problems, did not follow the courses or attend the conferences the associations organised. Finally, any active participation was rare, only about 5% of members attended the meetings regularly, something they tried to change through appeals published in their bulletins. (Instituto de Sociología Aplicada, 1969).

Besides these problems, the associations had to face, as we said earlier, much criticism. They were accused of being elitist, with a lack of dialogue between the management and members, and of being made up of middle to upper class families and of marginalising the neediest families. This is something that some actors of the family movement fiercely denied, citing the restricted economic criteria required to get public grants and subsidies and the large number of members receiving this aid (it was a way to prove that there were a lot of needy families in the associations). However, the truth is that most of the founders (and of those holding the managerial positions) came from well-off families, they had university qualifications (some were lawyers, doctors or teachers) and in some cases, they were well-connected with the local authorities. Parents' groups were also reproached for being impulsive and unthinking and for believing they were sufficiently qualified to participate, along with professionals, in the process of rehabilitating and re-educating their children (Puerto, 1970). Both facts were justified by the parents: it was necessary to be passionate to carry on their struggle, and participating in their children's recovery was a right inherent to their condition as parents and under no circumstances did this imply questioning the specialists' authority.

Finally, they were accused of not being very effective and for achieving little. Despite their efforts, the associations had managed to change the situation for intellectually disabled people and their families only slightly, among other reasons because they lacked the sufficient funding to provide new services and/or maintain the already existing ones,

and to employ trained staff to help run them. The associations depended on membership fees and on donations made by private institutions (such as building societies) or by citizens through charity events organised to raise funds. Public subsidies were, throughout this period, small and few and far between (Puerto, 1970). At the beginning of the 1970s, only 8% of intellectually disabled people in Spain received any kind of extra family care and there were still 11,000 persons living in psychiatric institutions. There were huge inequalities in protection depending on the age and level of intellectual disability of each person (the best being for children between 6 and 14 years with a moderate level of intellectual disability). Furthermore, there was a yawning gap between the real cost of the care and the public aid received, which moreover was limited and rather restrictive (Fierro, 1971).

In time, the actual associations themselves, or at least some of their members, started becoming more self-critical (Eguía, 1970; 1971). They acknowledged that it was necessary to make membership more attractive, offering support services to the worst-affected families. It was also essential to put the management of the associations into the hands of full-time, qualified teams, and to incorporate new, young people (interested citizens or siblings of those with intellectual disability) for executive and management tasks. These changes had to be accompanied —and this is the most interesting point— by a transformation in the thinking of the parents' groups. They had to reassess the role that their intellectually disabled children had to play in the associations. The idea to consider them as "children who never grew up" was, in some activists' opinion, inaccurate and paternalistic. If parents were really fighting to ensure their access to rights, they should allow them to speak out about their experiences and to make decisions about their future (Raventós, 1972).15 Lastly, associations had to take on a more critical posture, moving on in a determined way to the nonconformity that had inspired the pioneers of the associative movement (De Azúa, 1970; Azúa, 1972).

## 4.1. Asserting non-conformism

From 1970 onwards, vindication became the focus point on the pages of FEAP's publications<sup>16</sup>. The editorial team's rhetoric became increasingly critical regarding the government's inactivity and the dynamics of the associations themselves. In or-

der to bring about any real social change parent's groups had to become pressure groups, to be critical and to tackle intellectual disability as a political issue. Only by using social policy in terms of justice and rights, which exceeded the previous criteria of just charity, could "both the guiding principle of total care for intellectually disabled people and the principle of practical and political equal opportunities be carried out".<sup>17</sup>

The politicisation of the problems concerning intellectually disabled people generated suspicion amongst the associations themselves. 18 Through their promotional and management work for the centres, some groups had strengthened their relationship with the government. They had became consultants or even had incorporated representatives from the public administration onto their boards. Furthermore, the public subsidies they received made them feel that they were indebted to the Francoist government, although aids were scarce and poorly funded. For this reason, even if associations felt disappointed due to the "non-political" action of the government, they often settled for ad hoc solutions that profited specific groups or centres, without showing any kind of solidarity for the other associations. This contradiction was denounced from the pages of the magazine "Siglo Cero":

The questioning of the State agencies is so mild, it can hardly be heard. The associations define themselves as 'pressure groups'. But, what kind of pressure and against whom? They place more pressure on the man in the street than on the public authorities. With any officials from the administration, the only pressure is a handshake. The principle of 'apoliticism' of the associations is, in practice, translated into an abandonment of their critical function against the Administration's actions and omissions. However narrow the institutional and legal framework might be in which this critical function might be exercised today, the truth is that it allows some movements which we have never even attempted. Some movements of criticism and complaint that are possible even from within the supposed policies set down here and now by the executive power.19

The moment had arrived for the associations to take up positions regarding relevant questions such as economic inequality, working conditions and even citizen participation.<sup>20</sup> It was time to aim at promoting social changes with a wider scope. It was necessary for their members to become convinced of the fact that the problems of the people they rep-

resented were structurally linked to society's problems in general. The marginalisation of intellectually disabled people was just another point within social marginalisation. The difficulties that they found when attempting to gain access to education, care or work were connected to the deficiencies of the educational system, the social security system, the scarcity of the healthcare infrastructures and the high rates of unemployment in the country at this time. Fighting to improve the living conditions of Spaniards in general was the way to really transform the lives of people with intellectual disabilities, ensuring their access to the rights and welfare that corresponded to them as citizens.

#### **CONCLUSIONS**

By the end of the dictatorship, parents' associations were aware that their task was incomplete and knew that, in a way, they had failed to bring about changes in the lives of their intellectually disabled children. When advocating social rights, the dictatorship answered with a weak system of social services and subsidies. A paternalistic solution that made them dependent and pushed them into the dilemma of choosing between solving the most urgent needs and fighting for a more in depth political change. Associations' claim for specific care and protection achieved the recognition of their children's specificities, but their hope of raising public awareness to make them regarded as equal citizens was not fulfilled. Nonetheless, given the barriers they faced and the context of lack of freedom in which they were acting, the progress made during this time was remarkable. By becoming poles for the construction of the identity of intellectually disabled persons, defenders of their rights, and founders and managers of specialised institutions and services, self-organised parents groups played a central role in constructing the field of intellectual disability in Spain. Their work served to make intellectually disabled people visible and to legitimise their demands, leading the way toward the greater changes that would come with democracy.

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#### **NOTES**

- There are also not many studies focused on physical and sensorial disabled people associations during the dictatorship (Vilá, 1994; Fortún, 1998; Rodríguez, 2012; Bregain, 2013a).
- Carme Molinero has stressed how the social policies designed by the Franco's regime aimed both to improve the life of the nation's offspring and to mould the lifestyle and thoughts of the population in accord with the new social agenda. Besides, social policies were going to serve to legitimate the regime and create stability through social consensus (Molinero, 2005).
- 3. "El nacimiento de las asociaciones. Entrevista con Ernesto Puerto", *Siglo Cero*, 95, 1984, pp. 12-14, p.13.
- 4. Ibid, p.12.
- The Movimiento Nacional (National Movement) was the only political party allowed by the Franco's regime, which purported to be the only channel of participation to Spanish public life. It responded to a doctrine of corporatism in which only so-called "natural entities" could express themselves: families, municipalities and unions (Pecharromán, 2013).
- 6. Ibid, p.13.
- El problema de los niños subnormales, Madrid, Servicio Nacional de Asociaciones Familiares, 1964.
- Nowadays, the FEAPS maintains its acronym but it has changed its name: Spanish Confederation of organizations for people with intellectual disabilities (http://www.feaps. org/).
- Law 191/1964 of December 24th (Head of State, B.O.E. 28-12-1964, nº 311). Until that moment the creation of the associations was regulated by the Decree of January 25th 1941 (Ministry of the Interior, B.O.E. 06-02-1941, nº 37)

- 10. "Editorial. Una bandera, los Subnormales", *Boletín de la FEAPS*, 2, 1967, pp. 3-5.
- 11. "Editorial. Pararse a pensar", Siglo Cero, 30, 1973, pp. 3-4, p. 4.
- 12. "¿Adiós a la palabra subnormal?", Voces de la FEAPS, 39, 1974.
- 13. There were another three national conferences on intellectual disability in 1967, 1969 and 1972.
- 14. In the posters used in the 1967 campaign there were messages like these: "Do you know what a subnormal child is? He is not a child without future, he lives with our hope"; "He is not an 'isolated child'. He is integrated in our love. With your help, he will be useful for a generous society", (Boletín de la FEAPS,1, 1967, p. 28)
- 15. "Editorial. Pararse a pensar", Siglo Cero, 30, 1973, pp. 3-4.
- In the seventies, the director of both publications was the writer, psychologist and theologist Alfredo Fierro. His coworker was the philosopher and theologist Julian Abad Caia.
- 17. "El movimiento asociativo pro-subnormales en España", Boletín de la FEAPS, 13, 1970, pp. 5-10, p. 9.
- 18. "Editorial. Los subnormales problema político", Siglo Cero, 28, 1973, p. 3
- "Editorial. Estado y sociedad", Siglo Cero, 31, 1974, pp. 3-4, p. 4.
- 20. "Editorial. Teoría sociológica y estrategia política", Siglo Cero, 33, 1974, p. 3.
- 21. "Editorial. Cambiemos de conversación", Voces de la FEAPS, 50, 1975.

## **BIBLIOGRAPHY**

Abad, Julián (1972), "Ayúdame a seguir", Voces de la FEAPS, 17.

Álvarez Solis, Cristina (2012), La influencia de "El Norte de Castilla" en la creación del movimiento de familias de personas con discapacidad intelectual: el caso de Asprona Valladolid, Valladolid, Universidad de Valladolid, Trabajo Fin de Master, [on line], available at: http://uvadoc.uva.es/bitstream/10324/1789/1/TFM-F%2030.PDF, [retrieved on 16-11-2015].

Álvarez Urricelqui, Maria Jesús (2009), "El movimiento asociativo de familias y atención educativa a las personas con discapacidad intelectual: ANFAS 1961-2007". In: Berruezo, Maria

Reyes; Conejero, Susana (coords.), El largo camino hacia una educación inclusiva: la educación especial y social del siglo XIX a nuestros días, Pamplona, Universidad Pública de Navarra, pp. 565-574.

Arbelo, Antonio (1968), "El problema nacional de los niños subnormales". In: *Niños Subnormales. Segunda Ponencia al XII Congreso Nacional de Pediatría (21-25 de octubre de 1968),* Granada, s.n., pp. 1-30.

Azúa, Luis de (1969), "¿Qué significa para España y para usted el subnormal?", Boletín de la FEAPS, 8, pp. 33-35.

- Azúa, Luis de (1970), "De la resignación al inconformismo. El movimiento asociativo familiar pro-subnormales en España", In: *Deficiencia mental, cuestión urgente*. Madrid: Secretariado de Educación Especial, pp. 102-112.
- Azúa, Paulino (1972), "Volver al inconformismo", Voces de la FEAPS, 25.
- Ballester, Rosa (2012), "Los organismos sanitarios internacionales y la rehabilitación de los niños con discapacidades físicas. El caso español como modelo (1948-1975)", Estudos do seculo XX, 12, pp. 87-102.
- Barral, Catherine (2007), "Disabled Persons' Associations in France", Scandinavian Journal of Disability Research, 9 (3-4), pp. 214-236.
- Bittini, Eduardo (1973), "Nuestra problemática: una necesaria reforma de nuestras asociaciones", *Afanias*, 2, pp. 20-25.
- Boggs, Elisabeth, M. (1963), "New hope for the retarded", *The Rotarian*, 103 (1), pp. 22-28.
- Borreguero, Luis; Ferrero, Afrodisio (1964), "Panorama internacional del problema de los niños subnormales". In: *El problema de los niños subnormales*, Madrid, Servicio Nacional de Asociaciones Familiares, pp. 321-338.
- Bregain, Gildas (2013a), "'Nous ne demandons pas la charité. Nous voulons du travail!' La politique franquiste d'assistance aux invalides", Alter. European Journal of Disability Research, 7 (3), pp. 206-221.
- Bregain, Gildas (2013b), "An entangled perspective on disability history: the disability protests in Argentina, Brazil and Spain, 1968-1982". In: Barsch, Sebastian; Klein, Anne; Verstraete, Pieter (eds), *The imperfect historian*, Frankfurt and Main, Peter Frank Edition, pp. 133-153.
- Carey, Allison C. (2009), "The Rise of the parents' movement and the special child". In: On the margins of Citizenship. Intellectual disability and civil rights in twentieth-century America, Philadelphia, Temple University Press, pp. 105-133.
- Castles, Katherine (2004), "'Nice, Average Americans'. Postwar Parents's Groups and the Defense of the Normal Family". In: Noll, Steven; Trent, James W. (eds), Mental Retardation in America. A historical Reader, New York & London, New York University Press, pp. 351-370.
- DEL Cura, Mercedes (2011), Medicina y pedagogía: la construcción de la categoría "infancia anormal" en España (1900-1939), Madrid, CSIC.
- Del Cura, Mercedes (2016), "La subnormalidad a debate: discursos y practicas sobre la discapacidad intelectual en el segundo Franquismo", *História, Ciência, Saúde-Manguinhos* (in press)
- Dybwad, Rosemary F. (1966), "The widening role of parent organizations around the world". In: Selected convention

- papers. Perspectives in theory and practice (41st Annual Convention, Council for Exceptional Children, National Education Association, Philadelphia), Washington, Bureau of Education, pp. 59-63.
- Dybwad, Rosemary F. (1990), Perspectives on a parent movement: the revolt of parents of children with intellectual limitations, Cambridge, MA, Brookline Books.
- Earl, Dave (2011), "'A group of parents came together': parent advocacy groups for children with intellectual disabilities in post-world war II Australia", *Health and History*, 13 (2), pp. 84-103.
- Eguía, José Ignacio (1970), "Problemas de nuestras asociaciones", *Boletín de la FEAPS*, 16, pp. 21-32.
- Eguía, José Ignacio (1971), "Hacia otra década", Boletín de la FEAPS, 19, pp. 19-25.
- Espinosa, Che (coord.) (2012), Asprona 50 años, 1962-2012, Valladolid, Asprona.
- Fierro, Alfredo (1971), "Los subnormales en España. Análisis de necesidades y recursos", Boletín de la FEAPS, 18, pp. 7-18.
- Fortún, Valentín (1998), La creación e implantación de la Organización Nacional de Ciegos Españoles: 1938-1948, Pamplona, Universidad de Navarra.
- García, Víctor (1958), "Panorama de la Educación especial", *Bordón*, 10 (77), pp. 287-304.
- Instituto de Sociología Aplicada (1969), Estudio sociológico sobre los subnormales en España, Madrid, Euramérica.
- International League of Societies for the Mentally Handicapped (1967), The development of national Voluntary organisations for the mentally handicapped. Report of a symposium held in the Maison de l'Europe, Strasbourg.
- Jones, Kathleen W. (2004), "Education for Children with Mental Retardation. Parent activism, Public Policy, and Family Ideology in the 1950s". In: Noll, Steven; Trent, James W. (eds), Mental Retardation in America. A historical Reader, New York & London, New York University Press, pp. 322-350.
- Jordana de Pozas, Jorge (1984), "Ayer y hoy de las asociaciones", *Siglo Cero*, 95, pp. 15-17.
- López Iglesias, Javier (2014), 50 años con las personas con discapacidad intelectual: FEAPS, 50 Aniversario, Madrid: FEAPS.
- Martínez-Pérez, José y Del Cura, Mercedes (2015), "Bolstering the Greatness of the Homeland. Productivity, Disability and Medicine in Franco's Spain (1938-1966)", Social History of Medicine, 28 (4), pp. 805-824.
- Maza Zorrilla, Elena (2008), "Panem et circenses. Cultura asociativa en el franquismo", *Alcores*, 6, pp. 83-112.

- Molina, Fernando (2008), "La Asociación Vizcaína pro-subnormales (1962-1982)". In: *Lantegui Batuak. 25 años trabajando en Bizkaia (1983-2008),* Bizkaia, Fundación Lantegui Batuak, pp. 17-47.
- Molinero, Carme (2005), La captación de las masas: política social y propaganda en el régimen franquista, Cátedra, Madrid
- Pardo, Rosa (2008), "La salida del aislamiento: la década de los cincuenta". In: Mateos, Abdón (ed.), *La España de los cincuenta*, Madrid, Eneida, p. 109-134.
- Pecharromán, Julio Gil (2013), El Movimiento Nacional (1937-1977), Barcelona, Planeta.
- Pérez Marín, Arturo (1968), "Editorial, ¿han llegado a su máximo ya las asociaciones de padres y protectores de subnormales?", Boletín de la FEAPS, 4, pp. 3-6.
- Puerto García, Ernesto (1964), "La Federación Nacional de Asociaciones de Padres de Subnormales". In: *El problema de los niños subnormales*, Madrid, Servicio Nacional de Asociaciones Familiares, pp. 247-251.
- Puerto García, Ernesto (1970), "Función de las asociaciones de padres y familiares de subnormales". In: *Terceras Jornadas Técnicas de estudio sobre problemas de los subnormales*, Guadalajara, Delegación Nacional de la Familia, pp. 293-320.
- Puerto, Mario (2014), "Quisiera contaros...los orígenes". In: López Iglesias, Javier, 50 años con las personas con discapacidad intelectual: FEAPS, 50 Aniversario, Madrid, FEAPS, pp.
- Radcliff, Paloma (2009), "Las asociaciones y los orígenes sociales de la transición en el segundo franquismo". In: Townson, Nigel (ed.), *España en cambio: el Segundo Franquismo*, 1959-1975, Madrid, Siglo XXI, pp. 129-155 [English edition by Palgrave MacMillan, 2007].

- Raventós Fatjo, Jesús (1964), "Consideraciones sociales y educativas". In *El problema de los niños subnormales*, Madrid, Servicio Nacional de Asociaciones Familiares, pp. 307-313.
- Raventós Fatjo, Jesús (1972), "Lugar del subnormal adulto en la sociedad", *Boletín de la FEAPS*, 21, pp. 13-15.
- Richards, Michael (1998), A time of silence. Civil War and the culture of repression in Franco's Spain, 1936-1945, Cambridge, Cambridge University Press, 1998 [Spanish edition by Critica, 1999].
- Rodríguez, Juan Antonio (2012), "Las secuelas sociales de la polio: los inicios del movimiento asociativo en España 1957-1975", *Dynamis*, 32 (2), pp. 391-414
- Sánchez Llamosas, José, P. (1972), "Nuestra problemática: Asociaciones y obras sociales", *Afanias*, 1, pp. 26-27.
- Sánchez, Isidro (2005), "El miedo. Ley para todos. Asociacionismo y sociabilidad durante la dictadura franquista". In: Ortiz Heras, Manuel (coord.), *Memoria e historia del Franquismo: V encuentro de investigadores del franquismo*, Cuenca, Universidad de Castilla-La Mancha, pp. 101-152.
- Schianchi, Mateo (2014), "Associations of people with disabilities in Italy: a short history", *Modern Italy*, 19 (2), pp. 121-133.
- Sierra, Gregorio (1968), "¿Subnormales?", Boletín informativo ANIC (Zaragoza), 37.
- Suárez de Puga, César; Buceta Facorro, Emilio (1964), "Organización de las asociaciones familiares ante el problema". In: *El problema de los niños subnormales*, Madrid, Servicio Nacional de Asociaciones Familiares, pp. 241-251.
- Vilá, Antoni (coord.) (1994), *Crónica de una lucha por la igual-dad*, Barcelona, Instituto Guttman.
- WHO (1954), *The Mentally Subnormal Child*, Geneva, World Health Organization, Technical Report Series, nº 75.