



2.14 Spain

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2.14 *Introduction*

Spain is a modern country with a developed social model that provides funds to cope with the problems derived from the needs of disabled people. The government provides to different channels to reach the disabled. On one hand it has an established method of paying pensions to disabled people who fulfill a set of requirements, that is through the INSS (Instituto Nacional de la Seguridad Social). On the other hand, national and local governments use disabled NGOs to channel funds that come from the national budget and are supposed to reach disabled people. These funds are usually oriented to tasks such as home help, escorting, buying technical aids, day and rehabilitation centers, etc.

The state itself has a secretary of ministry (Ministerio de Trabajo - Secretaría de Asuntos Sociales) devoted to this matters and an independent organism (Real Patronato de Atención y Prevención de Minusvalías) that is in charge of promoting lines of action in order to activate the disabled's initiatives.

Spanish disabilities NGOs world is rather complex and unstructured, but at the same time rather developed. There is a single committee that deals with the government, that is CERMI (Consejo Estatal de Representación de Minusválidos). CERMI is the head umbrella organization and has representatives from different disabilities: blind, deaf, physical and psychical.

Blind disabled people, estimated in 50.000 all gather around a single organization, ONCE (Organización Nacional de Ciegos de España). ONCE is a very powerful organization that has one of the most famous lotteries in Spain. It handles around 2.500 MECU per year. Part of the money handled by ONCE goes to people with other disabilities through Fundación ONCE.

Deaf disabled people, estimated to add up to 1.2 million, have two main organizations, one that congregates deaf people (CNSE) and another one that congregates the parents with deaf children (FIAPAS).

People with psychical disabilities gather around main organization (FEAPS).



Physical disabled are probably the most fragmented group. Around 1 million people are represented in CERMI by two major organizations COCEMFE (Confederación Coordinadora Estatal de Minusválidos Físicos de España) and PREDIF (Plataforma Representativa Estatal de Discapitados).

All together, there are around 900 disabled related NGOs for a population of 39 million and an estimated number of 2 million of disabled people.

Most Spanish disabled organizations are run by disabled people, generating a better functioning schema.

The national level associations usually have a federal organization. They have regional representations which themselves divide in local associations. This structure is not always fulfilled and there are regional end/or local gaps. Nevertheless, in this approach, information follows a top-down flow, and information goes from national to regional level, and then on to local level.

2.14.2 *User participation*

All these organizations participate in a different degree in several activities all over the country, representing their affiliate's interests and fighting for a full social integration. Most of them just have a little office and a small publications where they provide information to their affiliates. User affiliation is considered to be high, although there are no statistics that support this statement.

Representatives of many associations participate in several forums in order to influence in social evolution. The most common activity is attendance to meetings and social events, although many are starting to go one step further and take active policies that ensure a shorter term goal achievement.

CERMI has actively participated in the Disability and Employment Plan recently approved by the Spanish government.

ONCE and Fundación ONCE have created and acquired companies in order to let people with disabilities run them themselves, with great success.



COCEMFE has followed ONCE's example and is creating its own companies, run mainly by disabled users.

Many local organizations, such as ASPAYM are also setting new companies, specially in the field of technical aids commercialization.

All of these and the rest of the organization get in touch with local authorities in order to work together in tasks such as physical barrier removal, social care, formation, etc.

COCEMFE, for example, organizes every year a set of vacation trips specially designed for physical disabled people, including escorting and very low prices.

2.14.3 *R&D user involvement*

All user organizations have recently realized that it is important to participate directly in the R&D process and try to influence the process in the best way they can.

They are actively trying to be present in European projects of the programs HORIZON and TIDE, and the national program PITER.

CERMI, COCEMFE and ONCE are present in the two standardization groups on technology and disabilities.

ONCE, Fundación ONCE, COCEMFE and CNSE promote and finance research and development projects in universities departments, as well as with research centers.

ONCE has recently signed a contract directly with Microsoft in the US in order to make the next version of their Windows computer operating system accessible for blind people. ONCE pays for the engineering force that has been included in the Microsoft's work team to achieve that goal.

COCEMFE has actively promoted a Spanish standard on computer accessibility, which will be the first standard in the world concerning this subject.



Fundación ONCE has created a factory that makes electric wheelchairs in Spain at a very competitive price, and has developed its own distribution chain in order to be more cost-effective.

COCEMFE is asked more and more often to participate in R&D projects related with technology, representing the user's point of view, and therefore intervening in the requirement definition and test phases of the projects.

Punctual non-organized user participation in R&D projects is also a very important way in which user needs are transmitted to the R&D world. Following is a set of experiences in this way, most of them under the umbrella of the PITER program.

Tetranauta and SIRIUS are two projects on improving electrical wheelchair control systems in which users are represented indirectly through the Hospital Nacional de Paraplégicos, a spinal cord injuries dedicated hospital in Toledo. Two rehabilitation doctors participate in the program transmitting their experience on direct contact with patients in the hospital.

TUTOR is a project with the goal on designing a cognitive help system to improve domestic task interaction for psychically impaired people. A panel of experts and user groups was set up in order to provide real experience with the system.

The Polytechnic University of Madrid has developed a text telephone system in which users have participated heavily through requirement definition, progress follow-ups and product testing. In this case, user representation has been granted by formal deaf associations.

The same university has developed a speech synthesizer with different types of software to provide vocal rehabilitation, foreign language teaching for disabled, etc. In this case users were represented by logopedists who use this tools directly with the users.



2.14.4 *User participation factinos*

In all the examples mentioned above, user participation has been done on a voluntary basis. User representatives attend to previously designated meetings, their costs being covered by the association.

In the Microsoft-ONCE project, ONCE has been paying the expenses of its engineers while they have been in Microsoft's headquarters in Washington (USA). But this engineers were not users themselves.

There is no formal structure for user participation, and every company or center that starts a new project has to go through the process of locating a user organization willing to provide a fairly well prepared user (which is not an obvious task). It is true that everyone prefers a formal user association representative than a single non-associated user, even if the latter is better prepared.

Sometimes, user participation is granted through people in the staff of the association. This staff member is not always handicapped itself and has usually no choice but to assist to the meetings. Staff gets paid, and therefore their presence is granted whilst a voluntary user may drop out at any stage.

There's also no formal established way to find out who's doing what in user participation through the country, not even within individual associations.

Not many different users are involved in user participation in R&D projects, and therefore most of them form a closed circle to which everybody addresses their calls, leading to a blocking situation.

User political representatives have a rough time trying to find prepared users for user participation, and on the other hand, have very little to offer, as no money or continuous work is granted.

2.14.5 *Spanish User Organisations with Activities in the Rehabilitation Technology Framework*

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