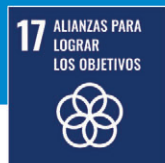




# Guide to the promotion of accessible governance



In collaboration with:



 POR SOLIDARIDAD  
OTROS FINES DE INTERÉS SOCIAL





# Guide to the promotion of accessible governance in **DOWN ESPAÑA** and its **Affiliate Organizations**

In collaboration with:



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## DOWN ESPAÑA

Our thanks to the National Network of Independent Living RNVI of DOWN ESPAÑA and its Accessible Governance Commission for their work and support in the development of this guide.

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#### DOWN ESPAÑA:

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CERMI Award for the Best Associative Trajectory

Magisterio Award for the Protagonists of Education

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Solidarity Award from the Spanish Association of Publishers of Periodicals Publications

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# Introduction

In recent years, DOWN ESPAÑA and its affiliate organizations have launched different actions to reflect on the concept of “**Accessible Governance**”, and to analyse the **participation** of people with Down syndrome in the associative world and in other community spaces. These actions have begun with an analysis of the real level of participation of the group, through the elaboration of specific questionnaires, and have continued with the development of some specific proposals, such as:

- Creation of working committees on participation and governance.
- Creation of groups of self-managers at affiliate organizations
- Incorporation of the figure of representatives (people with Down syndrome and intellectual disability) in the National Networks of DOWN ESPAÑA.
- Organization of days of reflection and promotion of participation in first person, with people themselves with Down syndrome.
- Sessions with families to promote the participation of their sons and daughters in associative life.
- Creation of protocols to improve accessibility in the day-to-day life of the organizations.
- Training and learning on how to apply Clear Communication in our organizations.

In this guide, we present the conclusions of the work done and give some clues to our affiliate organizations on how to implement internal processes to promote **Accessible Governance**.

All of this aimed at creating a strategy of transformation of our organizations (Associations and Foundations) so that they are not just organizations “for” people with Down syndrome, but also organizations “of” people with Down syndrome.

## What is Accessible Governance?

All actions aimed at making spaces for participation in our organizations more accessible.

It is about facilitating representative participation of all members of the organization in the governing bodies (Boards of Directors, Boards of Trustees, Assemblies of Partners), and in other activities such as self-management groups, consultation, committees, volunteer actions etc.

## 2.1 Accessibility

Accessible Governance aims to make the participation spaces of the associations more accessible to all the people who are part of the organizations: beneficiaries, families, volunteers, professionals, management teams, and committees.

Therefore, all actions in this area must be understood by **all people** and must guarantee universal cognitive accessibility.

### What does DOWN ESPAÑA mean by Universal Cognitive Accessibility?

1- DOWN ESPAÑA assumes the 2006 **Convention on the Rights of Persons with Disabilities** as the global reference framework, at the legal and principle level, which determines the policies for people with disabilities.

The Convention is based on principles such as:

- **Universal Design** in all goods, services, equipment and facilities, understanding it as: (art.4º.f and art.2º)
- The **accessibility** of the physical environment, transportation, information and communications (General Observation Noº2. Committee of the CDPD. 2014.)

2- In our country, the **General Disability Law** defines **Universal Accessibility** as the condition that environments, processes, goods, products and services must meet, **to be understandable, usable and practicable by all people in conditions of safety and comfort.**

3- In 2022, the amendment of the General Disability Law incorporates cognitive accessibility into the definition of universal accessibility and points out that *“cognitive accessibility is deployed and made effective through easy reading, alternative and augmentative communication systems, pictograms and other human and technological means available for that purpose”*.

With this new text, there is a risk of limiting the definition of cognitive accessibility by focusing it solely on supports for people with disabilities and losing its universal dimension. We no longer talk about accessibility “For all”.

4- From DOWN ESPAÑA we do not agree to limit cognitive accessibility only to supports. Following the line established by the Convention, we believe that it is necessary to promote a **Universal Cognitive Accessibility** that allows easy understanding of environments, services, products, messages and communications **to all the people.**

Specific support methodologies (Easy Reading or pictograms, for example) will be used in those cases where texts or communications of great difficulty of understanding, makes clear communication not enough to ensure that people with intellectual disabilities have an adequate understanding of the message. The objective is to ensure the right to understand of everybody and, therefore, the enjoyment of their rights in equal opportunities.



A few examples, as a summary:

- When measures are created to guarantee physical accessibility, the changes in the physical environment are built to be accessible to everyone. For example, we build ramps, doors, so that people with disabilities and without disabilities can enter, and we do not build different entrance doors for people on foot and people in wheelchairs.
- In inclusive schools, methodologies and techniques are developed so that all students (reliance to their condition and situation) access the contents, and the curricular adaptations are proposed as exceptional supports, justified only in case of special difficulty.

## UNIVERSAL DESIGN



### UN Convention on the Rights of Persons with Disabilities

“Universal Design” means that **all people** can use the design of products, environments, programs and services.

The “universal design” will not exclude **technical aids** for particular groups of people with disabilities, **when needed**.



## COGNITIVE ACCESSIBILITY



### UN Convention on the Rights of Persons with Disabilities

Relevant measures to **ensure access** for people with disabilities, **to information and communications** and to other services and facilities open to the public or to public use.

## UNIVERSAL COGNITIVE ACCESSIBILITY



### DOWN ESPAÑA 's Approach

The one that meets the necessary conditions to **ensure access**, and allow easy understanding and communication, **to all people**, of environments, services, products, messages and communications.

- 1- Promote a clear and simple communication that allows the easy understanding of all people, in all the goods, services and communications of our Organizations.
- 2- Use technical supports to ensure understanding by people with intellectual disabilities, when the complexity of the message requires it.

## Proposals on accessibility:

With this approach, DOWN ESPAÑA proposes **3 proposals for universal cognitive accessibility** to progressively incorporate into the structure of the Federation and its member organizations:

- 1- **That all internal and external communication materials are prepared with Clear Communication criteria to facilitate universal understanding:** internal documents, guides, publications, web pages, news, newsletters, etc.
2. **That only the texts and materials of a great difficulty of understanding have a version with support settings** such as Easy Reading, pictograms, etc.
3. **That our physical environments and spaces include elements of universal cognitive accessibility** with signage, images, colours, information and forms of use, understandable by all people.

## 2.2 Participation

The slogan “Nothing about us without us” reflects the philosophy of the rights of people with disabilities and defends their participation, which until now, in the case of people with intellectual disabilities, have been mostly exercised by other people: family members, professionals, etc.

These people continue to encounter attitudinal, physical, legal, economic, social and communication barriers that prevent their participation in the public life.

### What do we mean by participation?

The **Committee on the Rights of Persons with Disabilities** (an organ of independent experts that oversees the implementation of the Convention by the States Parties.) makes a series of proposals to promote the participation of people with intellectual disability. Among them:

1. Hold consultations that guarantee the opinion of people with disabilities on the issues of representation and organizations governance.
2. Actively incorporate people with disabilities into the governing bodies of their own organizations.

In this way, we will be encouraging the contribution of value on the part of the person and not just a passive participation as a user of a service.

In addition to consultations and governing bodies, social organizations have other spaces in which their members can participate and add value. The key is that the organization of those spaces is accessible, and guarantees a real and representative participation.

## What do we mean by real and representative participation?

The one in which the person with Down syndrome or intellectual disability expresses his own opinions or those of the group he represents, with their own language and way of expressing himself.

In order to occur, it must be guaranteed that the person understands the information offered to him, the participation mechanism and the type of participation that is being asked.

## The Spaces of Participation

The active participation of people with Down syndrome in their organizations can be organized through spaces such as the Assemblies of Partners, Boards of Directors, Boards of Trustees, groups of Self-Managers, Assemblies of Representatives, working groups, consultation groups etc.

These spaces must guarantee universal cognitive accessibility and must provide for technical and personnel support to be implemented, in case they are needed to guarantee a real and representative participation.

To ensure real and representative participation, previously we must:

- Preserve and support the exercise of the legal capacity of the person with Down syndrome.
- Create an environment conducive to the exercise of self-representation.
- Encourage organizations with maximum representation.
- Design and/or adapt accessible participation spaces: round tables, participatory dialogues, public hearings, surveys and online consultation.
- Consult people with Down syndrome and their organizations all the decisions of the public sphere.
- Supervise and facilitate the public leadership of organizations of people with Down syndrome.

## Where to participate

There are different **types of organizations and groups** where people with Down syndrome and other intellectual disabilities can participate:

- a) Organizations of relatives of people with Down syndrome who come together to promote the rights, interests, autonomy and active participation of their relatives.

For example: family members lead many of our Associations and Foundations.

- b) Coalitions or federations of different family organizations that come together to carry out common projects and represent those people, at the local, regional or national level.

For example: DOWN ESPAÑA.

- c) Coalitions or federations of different family organizations that come together to carry out common projects and represent those people internationally.

For example: EDSA (European Down Syndrome Association) DSI (Down Syndrome International) FIADOWN (The Ibero-American Federation of Down Syndrome).

- d) Other organizations that represent people with different types of disabilities before the Public Administration.

For example: CERMI, ONCE, Third Sector Platform, etc.

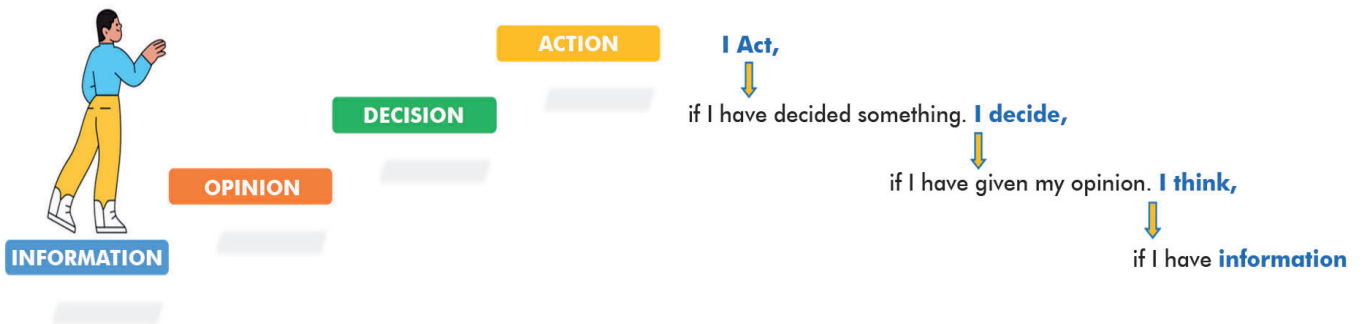
These organizations are “for” people with Down syndrome, that is, they work for their well-being and that of their families, represent their interests and defend their rights. In each organization, people with Down syndrome may have different degrees of participation, depending on the case.

Within these organizations, some groups “of” people with Down syndrome and other intellectual disabilities have been created. Decision-making, real, and representative participation are encouraged. In recent years, the people who participate in these groups, often-called “groups of self-managers” have exercised collective representation, inside or outside their organization, in events or media, for awareness, discussion and claim of their interests and collective rights.

Some of these groups have been constituted as representative Assemblies, such as: the Monserrat Trueta Human Rights Assembly of the Catalan Down Syndrome Foundation (FCSD)

The objective of DOWN ESPAÑA for the coming years is that all organizations “for” people with Down syndrome promote and incorporate these spaces of representation “of” people with Down syndrome in their structure of participation and governance, so that they stop “To be for the sake of Being” and move to “To be and participate” with all that that entails.

It is important to remember here the concept of the **Participation Ladder** as a basis for guaranteeing a real and representative participation:



## 3.1 Questionnaires for beneficiaries of affiliate organizations

Currently, there is a very low participation of people with Down syndrome in the governance of the organization that represent them. Whatever the type they are.

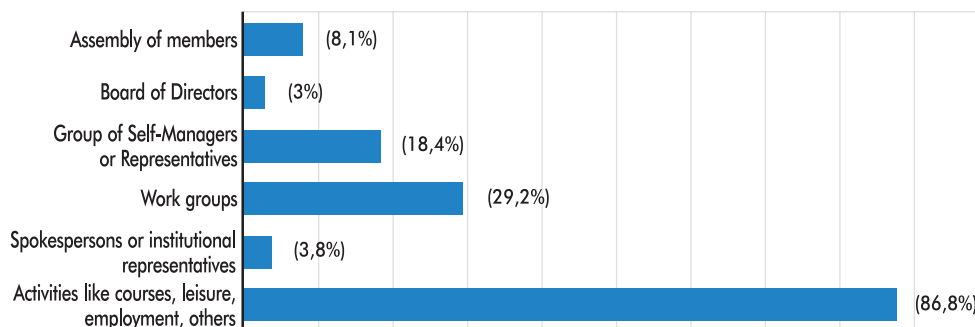
In order to have objective data, DOWN ESPAÑA has carried out an internal study in collaboration with its affiliate organizations to know the real level of social,

political and community participation of people with Down syndrome and other intellectual disabilities in Spain.

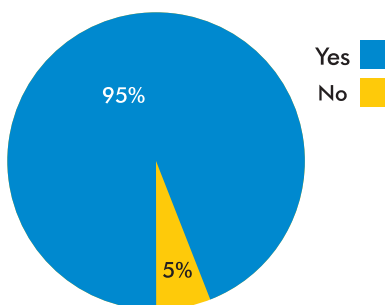
- Responses have been obtained from 506 beneficiaries of 30 organizations.
- The average age is 32.3 years.
- 52% are men and 48% are women.
- 52% have Down syndrome and 48% have another disability.

The results have been as follows:

### Question 1 What spaces or activities do you participate in at your Association or Foundation?



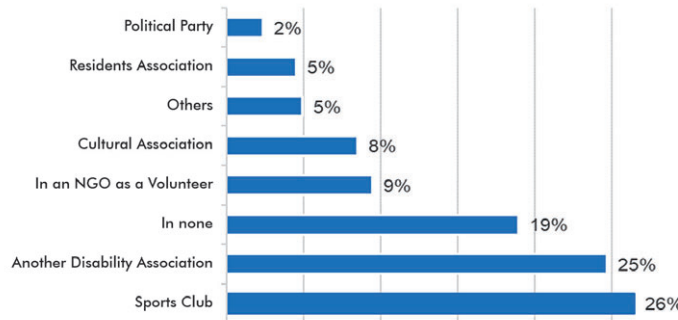
### Question 2 Do you think that your Association or Foundation takes into account your opinions and proposals?



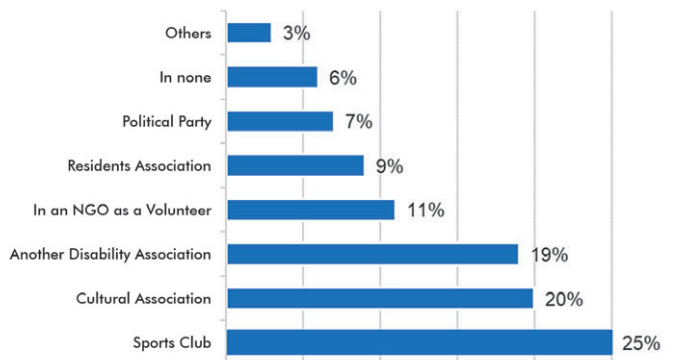
# 3

## DOWN ESPAÑA: the social and community participation of people with Down syndrome

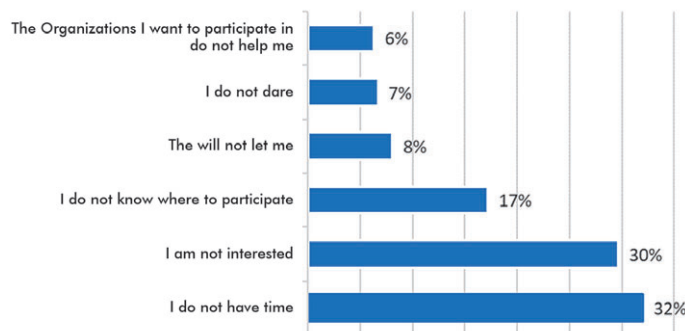
**Question 3 In addition to your Association or Foundation, are you a member of any of these organizations?**



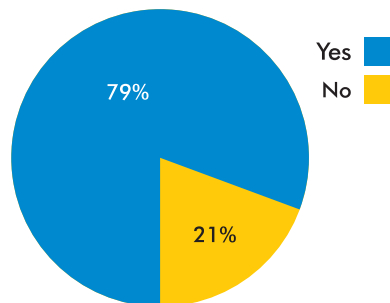
**Question 4 What organization you do not participate in, but would you like to participate?**



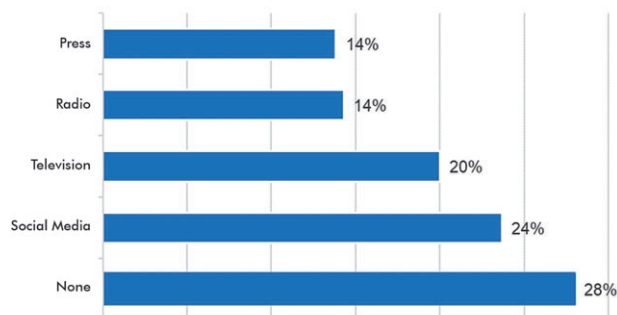
**Question 5 If you do not participate in any organization other than your Association of Foundation, what is the reason?**



## Question 6 Have you voted in some elections?



## Question 7 Have you ever participated in any of these media?



### Some conclusions:

- Participation in organizations is mostly done as a user of service and activities. The level of participation in governing bodies (Assemblies and Boards of Directors or Boards of Trustees) and participation as spokespersons or representatives of their institutions is very low.
- A positive aspect is that participation in working groups or groups of spokespersons or representatives appears with a little more weight.
- Despite the low active participation, most people feel that their views are taken into account by their organizations. This data indicates that the ideology of participation is there. The next step is to create structure.
- Sports, Leisure and Cultural Clubs and Associations, as well as other Associations in the disability sector are presented as the main channels for social participation outside the reference entities.

# 3

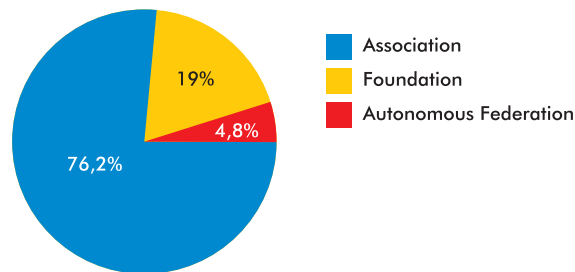
## DOWN ESPAÑA: the social and community participation of people with Down syndrome

- The main barriers to greater social participation come from the lack of time and the lack of interest. It would be desirable if these barriers stem from a lack of attractive options for the collective or based on their tastes and needs.
- Participation in the elections is quite high. Political participation is a very complex issue and would require a more specific study.
- Almost half of the people surveyed have participated in some media (television, press or radio) on behalf of their organizations. The rest do not participate through the media or do so through social networks.

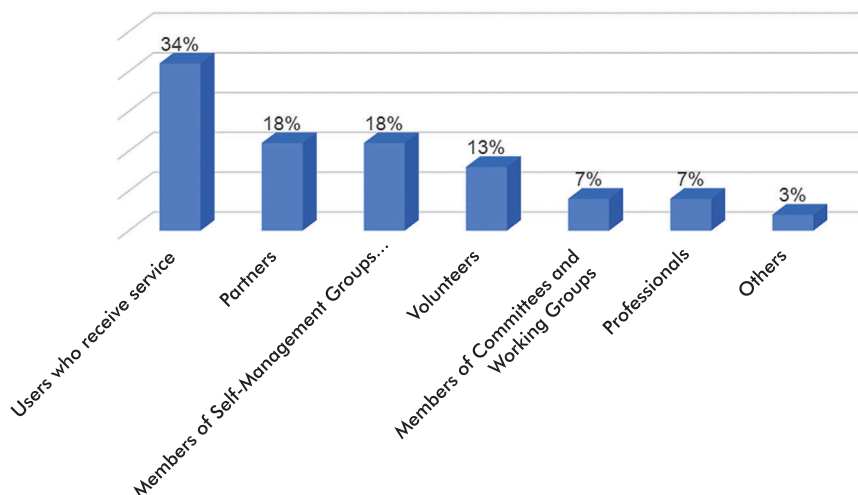
### 3.2 Questionnaires for professionals from Affiliate Organizations

- Responses have been obtained from 20 Affiliate Organizations.

#### Question 1 Type of entity

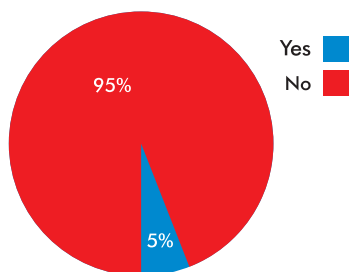


#### Question 2 Role that people with Down syndrome and intellectual disabilities have in the entity

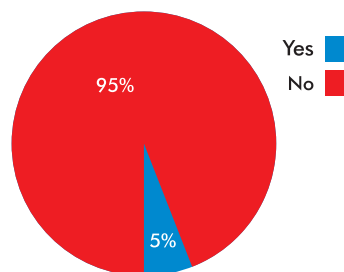




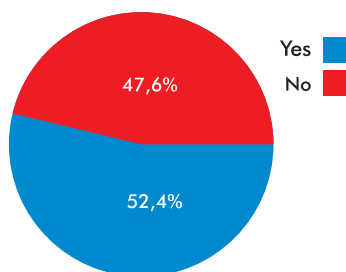
## Question 3 People with Down syndrome on Boards of Directors or Boards of Trustees



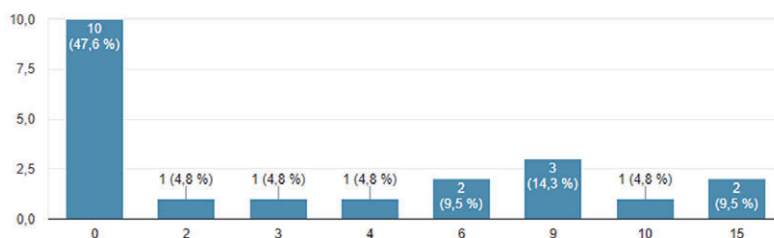
## Question 4 People with intellectual disability on Boards of Directors or Boards of Trustees



## Question 5 Does the entity have at least one Group of Self-Management and/or Representatives of Services?



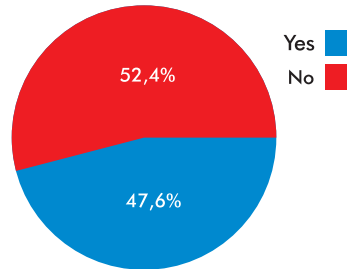
## Question 6 How many people with Down syndrome are part of the Group of Self-Managers and/or Service Representative?



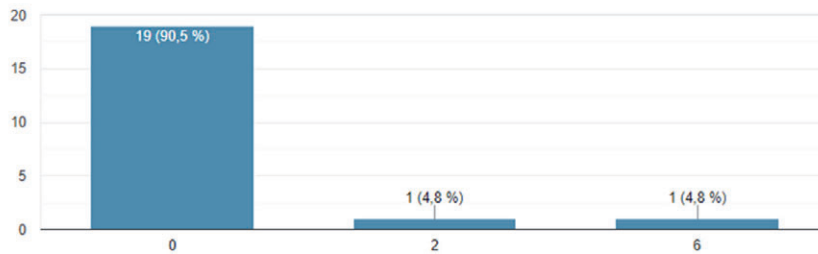
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## DOWN ESPANA: the social and community participation of people with Down syndrome

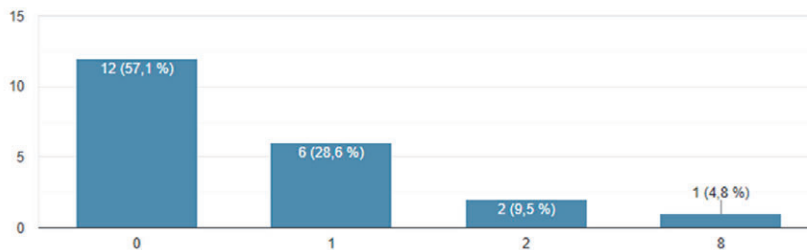
**Question 7 Are there any Working Groups or external Committees in your entity?**



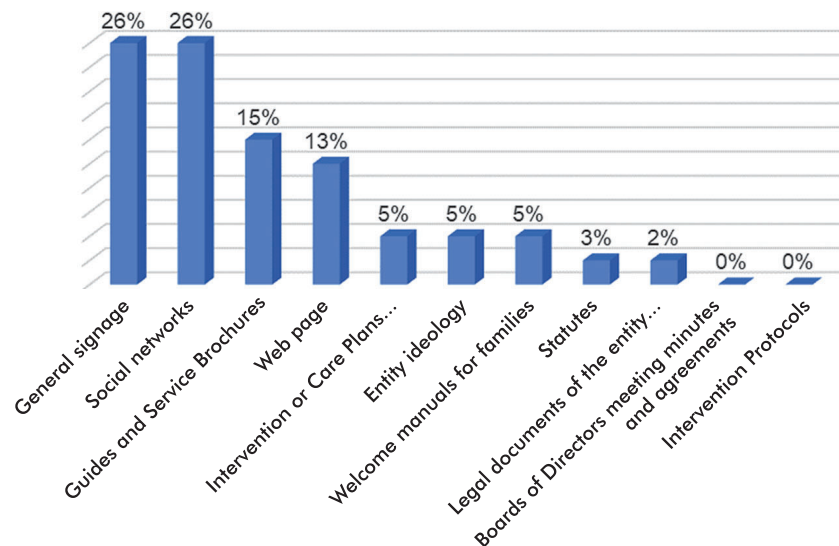
**Question 8 How many people with Down syndrome are part of these Working Groups or Committees?**



**Question 9 How many people with Down syndrome in the entity are enrolled in DOWN ESPANA National Networks?**



## Question 10 Of the present documents and informative supports of the entity, which are written according to cognitive accessibility criteria?



### Some conclusions:

- More than half of the beneficiaries participate as recipients of services or as partners of the organizations. 30% do it through groups of self-managers or as volunteer staff.
- In only 5% of cases, there are people with Down syndrome and/or intellectual disability on the Boards of Directors or Boards of Trustees of organizations.
- Half of the organizations have not yet created groups of service or self-management representatives. Despite this fact, this seems to be one of the most appropriate ways to promote a real and representative participation of people with Down syndrome.
- External Committees hinder representative participation due to their high degree of specialization.
- There are still many entities that have not yet incorporated the figure of the service representative into the National Networks.
- Further work should be done to encourage this type of participation and the conditions to ensure that it is representative and real.
- There is still a lot of work to be done in terms of promoting universal cognitive accessibility of communications and documentation in organizations. Particularly in relation to internal and statutory documents such as statutes, meeting minutes, agreements, etc.

# 4 Towards accessible governance in our organizations

## 4.1 How are our organizations?

Before entering into specific strategies and recommendations on governance and participation, it is necessary to know some basic details about the structure of the organizations that make up DOWN ESPAÑA.

### Associations and Foundations

People with Down syndrome and their families have joined and grouped themselves around different organizations to pursue these objectives:

1. Defend the rights of the collective.
2. Organize support services so that their children can develop an autonomous and independent life at the different stages of their lives.
3. Promote social inclusion of people through projects of personal autonomy and independent living.
4. Participate in cultural, sports and leisure activities.
5. Promote knowledge, research, innovation or social awareness about Down syndrome.
6. Help change the vision and social image of Down syndrome.

These organizations have been created mainly, with two legal formats, Associations and Foundations.

**Although they often share an ideology and work methodology, both types of organizations have differences in their internal composition and in the belonging relationships for their members.**

**In associations, the relationship is horizontal and participation is equal (we are talking about members). In Foundations the relationship is more vertical. The organization is oriented towards a project and we talk about users or beneficiaries.**

Likewise, it should be noted that Associations have full operational autonomy and Foundations are supervised by a public Protectorate.

### Governing bodies

Governing bodies are the spaces of maximum representation and decision-making of members of an organization.

In Associations, governing bodies are the “Assembly of Partners” and the “Board of Directors”.

In Foundations, the governing body is the “Board of Trustees”.

The “Assembly of Members” is the space where all members with voice and vote of an Association, can participate, vote and decide on matters that affect the general functioning of the organization.

The Assembly must meet at least once a year.

The Board of Directors and the Board of Trustees are the spaces where a group of members of the organization acts as representatives and heads of these organizations.

The Board of Trustees is made up of those persons, natural or legal (called “Trustees”) who have been initially appointed by the founder or founders of the organization.

The Board of Trustees is vested with all the powers of the administration and governance of the organization. It must meet at least twice a year.

The Board of Directors is composed of a group of people, elected by the Assembly of Members, who are responsible for managing the interests of the association in accordance with the provisions of the Assembly, under criteria of general representation, competence and responsible management.

Unlike the Foundations, where all the responsibilities of governance lie with the Board of Trustees, in the Associations, these tasks are shared between the Assembly and the Board of Directors.

The Boards of Directors are made up of the following figures:

## PRESIDENCY



*Directs and Represents the organization institutionally. Signs the agreements and looks for collaborations.*

## VICE PRESIDENCY



*Fulfills the functions of the Presidency when this one is not available.*

## SECRETARIAT



*Collects and takes minutes of all the decisions that are made in the meetings and Assemblies.*

## TREASURY



*Controls and supervises the organization's budget and the economic balance.*

## VOCALS



*Propose, deliberate and vote on the decisions made by the Board of Directors.*

***Supervise the professional team to ensure that the mission, vision and ideology of the Organization is fulfilled.***

## The professional teams

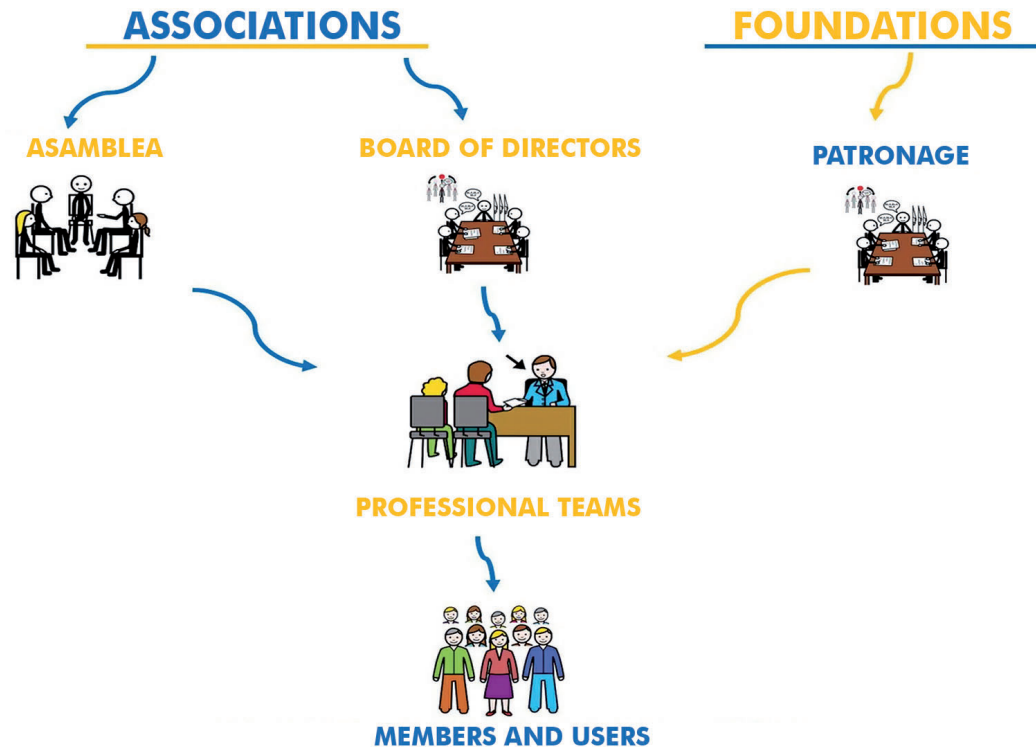
Organizations usually have paid professionals for the management and implementation of ongoing projects. These people do not usually form part of the governing bodies (Boards of Directors and Boards) and it is recommended that they do not do so.

If they do, it should be in a limited way (with partial agreements on the transfer of powers) so as not to alter the representative nature of families and people with Down syndrome of the organizations.

## The statutes

The Statutes are the documents that sets out the fundamental rules for the functioning of the Associations and Foundations.

In the case of Associations, the drafting, approval and modification of the statutes corresponds to the Assembly of Members. In Foundations, it is up to the Board of Trustees.



## Federations and Confederations

Federations are institutions that bring together organizations that share common interests, the same geographical location or the same care group.

Federations and Confederations are structured in the same way as Associations and are composed of the same governing bodies: Assembly of Members and Board of Directors.

The members of the Federation are the affiliate organizations themselves.

The Members' Assembly of a Federation is made up of persons acting on behalf of the affiliate organizations.

The Board of Directors is composed of representatives of the organisations who are elected in an

Assembly and who are responsible for the management of the Federation.

The Assembly is composed of accredited representatives who represent the affiliate organization.

In our Federation, we have:

- Regional Federations which group Down organizations from the same region.
- National Federation (DOWN ESPAÑA) which groups Associations, Foundations and Federations equally from all over the country.
- International Federations or Associations to which DOWN ESPAÑA belongs, and which group Associations and Federations of different Countries.

## ASSOCIATIONS & FOUNDATIONS



## REGIONAL FEDERATIONS



## NATIONAL FEDERATION



## INTERNATIONAL FEDERATION



### DOWN ESPAÑA

DOWN ESPAÑA is the Spanish Federation for Down syndrome.

It is made up of 88 Associations (data from 2022), Federations and Foundations that work primarily for people with Down syndrome and complementarily for people with other intellectual disabilities, in all Autonomous Communities of Spain.

Its main objectives are:

- 1- Represent people with Down syndrome and their families in Spain, fighting for defend their recognized in the International Convention on the Rights of Persons with Disabilities.
- 2- Carry out projects that improve quality of life and autonomy of people with Down syndrome at all life stages.
- 3- Offer knowledge, guidance and support to families of people with Down syndrome throughout Spain.
4. Enable the exchange of knowledge, best practices and projects among the organizations that make up the Federation.
- 5- Train professionals who work with people with Down syndrome to ensure that with their work improves the services provided by the organizations.

### Ideology of DOWN ESPAÑA:

All the organizations have a reason for being and a sense to exist.

In non-profit social organizations, this meaning is embodied as MISSION and OBJECTIVES in the Statutes and in the Ideology, and are specified in the successive work plans, strategic plans, etc.

DOWN ESPAÑA has approved in its General Assembly an ASSOCIATIVE IDEATORY which defines the ideological framework and the philosophy with which the organisation acts.

The main ideas are:

- Diversity Assessment.
- Personal autonomy.
- Inclusion.
- Universal design.
- Use of community resources and spaces.
- The person at the centre.
- Gender perspective.
- Unit.
- Responsible management.
- Neutrality.

All with respect for the fulfilment of the human rights of persons with disabilities, and therefore the Convention on the Rights of Persons with Disabilities.

# 4 Towards accessible governance in our organizations

All the federated entities that form part of DOWN ESPAÑA accept and make this ideology their own, as a guide for action.

## Specificity of Down syndrome:

In Spain, Down syndrome organizations arise to respond to the needs of people with Down syndrome and their families.

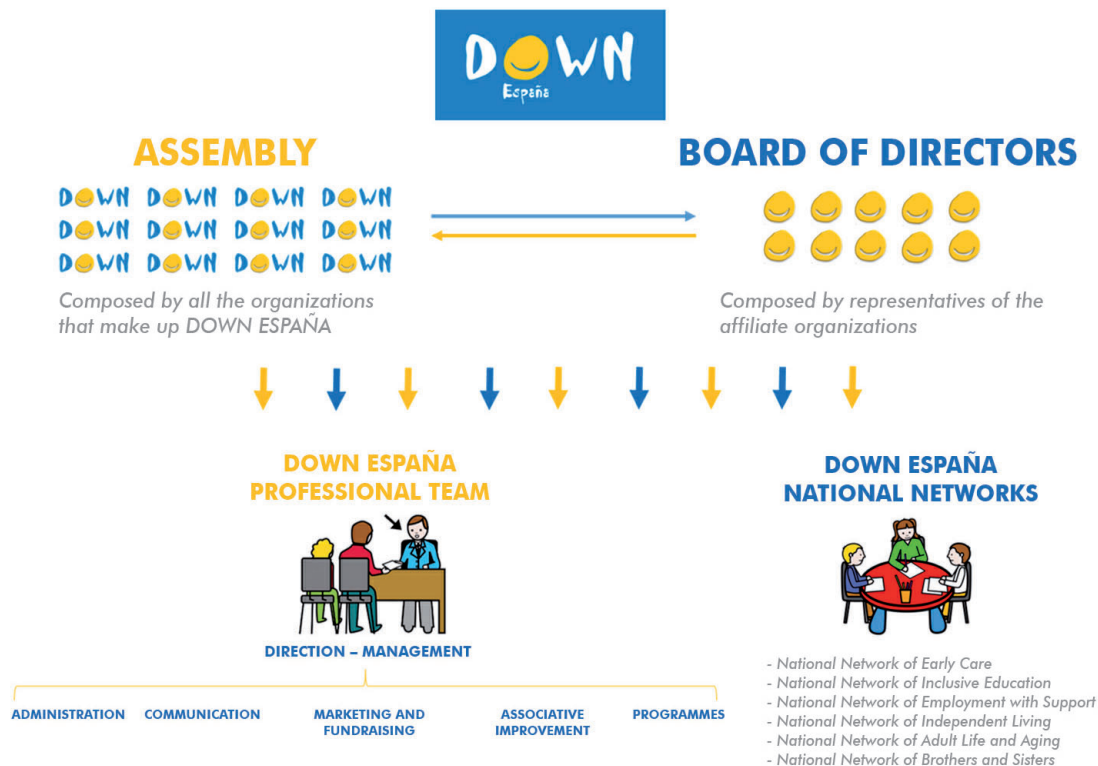
This Down syndrome-specific approach is not an exclusive approach (in our organizations there are also many other people with intellectual disabilities) but it is a priority, related to the needs of people with Down syndrome and proximity to the families, and

the absence of large institutionalized structures or merely professional management.

In coherence with this idea, DOWN ESPAÑA is a Federation made up of entities with full-fledged (with voice and vote) of family-based organization that are specifically or primarily oriented towards Down syndrome.

It is possible that organizations that do not have this Down syndrome specific or priority focus to be part of the Federation, but they can do so as adherent entities (with voice, but without vote. That is to say, that they cannot present members for executive positions, nor can they vote for them).

## DOWN ESPANA Structure:



<https://www.sindromedown.net/conocenos-2/>



DOWN ESPAÑA **Professional Team** consists of specialists from the social sector, organized in the following departments:

- 1- Management - Direction.
- 2- Administration.
- 3- Communication.
- 4- Marketing and Fundraising.
- 5- Associative Improvement.
- 6- Programmes

## The National Labour Networks

The National Networks are working groups made up of professionals from DOWN ESPAÑA and affiliate organizations, people with Down syndrome and intellectual disabilities and siblings representing the organizations.

Their objective is to exchange knowledge about Down syndrome, to carry out joint projects and too promote the effective and accessible participation of people with Down syndrome and intellectual disabilities.

Currently There are 6 National Networks in DOWN ESPAÑA:

- 1- National Network of Early Care.
- 2- National Network of Inclusive Education.
- 3- National Network of Employment with Support.
- 4- National Network of Independent Living.
- 5- National Network of Adult Life and Aging.
- 6- National Network of Brothers and Sisters.

## 4.2 How can our organizations be more accessible?

### General recommendations

In addition to the enforcement of relevant laws and regulations, there are a number of general measures that organizations can implement to transform their internal structures and make them more accessible.

For example:

- Implementing style of management, leadership and decision-making that guarantee the active participation of all members or stakeholders.
- Generate and foster a sense of ownership of all the people who relate to the organization (Promote the "Ladder of Participation" sequence)
- Train the governing bodies and professional teams in aspects related to accessibility, clear communication, autonomy, self-determination or diversity.
- Train people with Down syndrome in aspects related to accessibility, partnership, spokesperson, leadership, autonomy or diversity.
- Open and democratic processes to elect the person with Down syndrome who will participate in the representation spaces.
- Review communications from governing bodies towards the people interested in the organization under criteria of clear communication and easy reading when necessary.
- Review the protocols for convening, conducting and communicating of meetings, assemblies and work forums.
- To create intermediate spaces for communication and exchange between people with Down syndrome and their representatives, to ensure that the latter convey the interests and proposals of the collective to the governing bodies.

## Specific recommendations

We pointed out at the beginning of the guide that accessible governance is about making the spaces for participation in our organizations more accessible.

Therefore, if we want to put in place a strategy to improve governance throughout the organization, we will have to identify which are the **spaces for participation** in our organizations, know how they work and implement the necessary adjustments to make them more representative and accessible.

By analysing the internal structure of our organizations and their functioning, we can distinguish the following areas of participation.

- 1- Spaces for internal and external communication.
- 2- Spaces for meeting and decision-making.
- 3- Spaces for self-management and representation.
- 4- Spaces for consultation

## Internal and external communication spaces

Organizations communicate with people, collectives and institutions with which they relate. These communications are made through multiple channels within and outside the institution.

Even though the channel, the receiver or the message varies depending on what we pursue with each communicative action, the strategy behind all of them, internally and externally, should be the same and focus on **Universal Cognitive Accessibility**, or in other words "enabling easy understanding by all people".

To do this, at DOWN ESPAÑA we propose the use of clear and simple communication in all services, spaces and communication channels of the organization.

Our internal documents, guides, publications, web pages, news, newsletters, etc. must have a communicative style that allows the transmission of information in a simple, direct and effective way.

Communication that can be understood by all people and adapts to the channel through which it is transmitted.

Communication that can combine elements of written communication with more other graphic and visual ones to facilitate understanding.

**LIBRARY ACCESS RULES**

- 1- Access with food or drink is not allowed.
- 2- Use of mobile phone is not allowed.
- 3- Loan of books to people who are not members is not allowed.
- 4- Library hours are Monday to Friday from 10:00 a.m. to 2:00 p.m. and from 4:00 p.m. to 8:00 p.m. On Saturdays, access is only allowed in the mornings.



## LIBRARY

**HOURS**

- Monday to Friday from 10:00 am to 2:00 pm and from 4:00 pm to 8:00 pm
- Saturdays from 10:00 to 14:00

**RULES**

**BOOK LOANS ARE ONLY FOR MEMBERS**

We can see an explanatory guide on "Clear Communication" at the following link:

<https://comunicacionclara.com/>



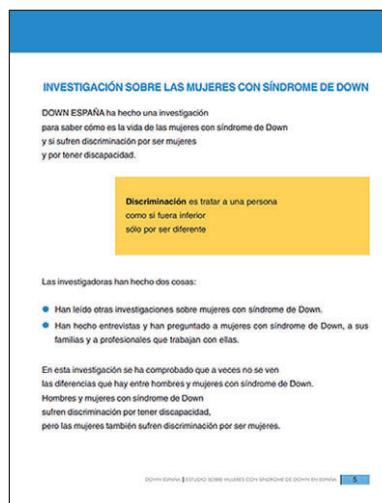
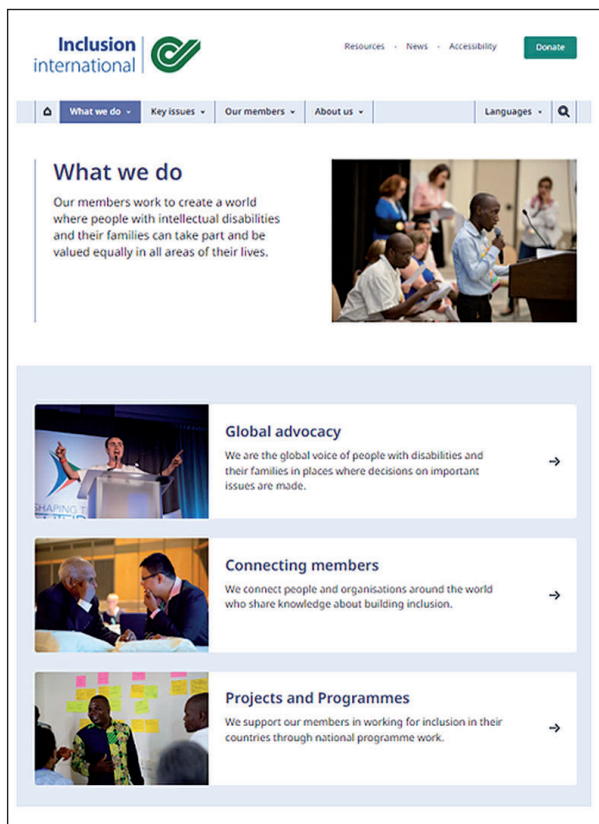
## Clear Language and Easy Language

Clear language aims to increase the effectiveness of the message. The message should be understood without the need to re-reading, well structured and not confusing.

Easy language (or easy-to-read language) is the language that should be used when the complexity of the message makes it necessary to adapt it so that it can be understood on equal terms by people with intellectual disabilities or reading difficulties.

### Some examples:

Clear and accessible communication on Websites.



Example of publication of DOWN ESPAÑA Easy Reading. "Women of courage. Study on reality and needs of women with Down syndrome in Spain".

- IDENTIFYING CATEGORIES
- USING SIMPLE PHRASES
- SUPPORTING THE MESSAGE WITH IMAGES
- EASY TO READ AND UNDERSTAND

<https://inclusion-international.org/what-we-do/>



Clear communication on Social Networks.



## Meeting and decision-making spaces

The governing bodies of organizations mainly use meetings (face-to-face or telematic) as a tool for internal coordination and decision-making.

In order to make meetings accessible and to ensure a real and representative participation of people with Down syndrome and intellectual disabilities in these spaces, such meetings must be effective. In order to achieve this, some criteria of structure and functioning must be taken into account:

### 1) Before the meeting:

- Call the meeting in advance.
- Send the agenda with the notice of meeting, following universal cognitive accessibility criteria: Understanding for all.

- The agenda should specify the topics of the meeting and a brief explanation of each one.
- Attach to the notice of the meeting the necessary working documents: minutes, reports, etc.
- Define the timetable and duration of the meeting and of each topic to be discussed.
- Plan deliberation, consultation or rest breaks during the meeting.
- Define the meeting place face-to-face or telematic (attach link).
- Identify the people who will participate in each topic of the meeting.
- Know characteristics and accessibility needs of the participants.
- Secure support staff for the meeting and define their roles.

### 2) During the meeting:

- Place the meeting: introduce the meeting, its participants, structure, objectives and agenda, so that everyone is aware of the expected performance.
- At the beginning of the meeting: read out the previous minutes in simple language, with a space for questions and doubts, and finally approve the minutes or not.
- Respect order of the topics to be discussed so as not to confuse the participants.
- Make a brief and simple presentation of each topic.
- Make a summary at the end of each topic, with the proposals or agreements to ensure their understanding.
- Use clear, well-placed language: use simple concepts, short sentences and at a slow oral speed, to be understandable to all.

- Avoid or explain specific technical terms that arise.
- Ask from time to time if the explanations are understood.
- Apply digital and cognitive accessibility resources in the technological resources used (visual presentations, videoconferencing systems, etc.).
- Conclude the meeting with a summary of all the topics and agreements adopted.

### 3) After the meeting

- Draft the minutes of the meeting in simple language, with individual or collective agreements and commitments of the participants.
- Send the minutes to the participants, allowing time for contributions.

In addition to personal support and accessibility criteria, of all meeting and decision-making spaces, participants should play a natural supportive role, facilitating access, belonging, communication, coexistence and the exercise of self-representation.

There are also other environmental factors, which contribute to improve access and participation of all people.

- A barrier-free physical environment.
- Availability of assistive visual technologies (large screens, large size of presentations, subtitles, etc.)
- Positive attitudes towards the participation of all people. Trust and respect.
- Guidelines that regulate participation.

## Management and self-representation spaces

### Groups of self-managers and representatives:

These are participation groups that have been generated within organizations “for” people with disabilities to favour the knowledge of their rights and duties, their collective vindication and the exercise of their self-determination.

Implies one of the first attempts we have known to give people voice and prominence, and begin to promote their participation in the governance of organizations.

Access to the group must be voluntary and motivated by active participation. Self-managing people manage their goals, objectives and collective activities, through the consensus of the participants. They have the support of a facilitator who accompanies them in their activities, without interfering with their self-determination. Participants can take basic previous training in self-management, human rights, communication skills, etc.

It is important for organizations to define the participation ways of self-management groups in the structure and functioning of their governance bodies, so that it is effective and transforming.

### The example of the National Networks:

#### The origin

- 1- In 2020, the National Network for Independent Living of DOWN ESPAÑA incorporated people with Down syndrome and intellectual disabilities into its functioning.
- 2- These people joined the Network as representatives of the independent living services of their organization.
- 3- Their mission is to convey their personal opinion and the contributions of the group of people to

whom they represent, concerning the Independent Living projects and services developed in the organizations.

- 4- Prior to the effective incorporation into the Network, a training was carried out for the representatives and they were assigned a support professional, who in most cases was the professional assigned to the Network.
- 5- To ensure real and representative participation, the Network created a working committee in charge of the creation of protocols and strategies to improve the accessibility of the Network's documents, conferences and meetings.
- 6- This commission is made up of professionals and service representatives.


## The current situation

Thanks to the work of the National Network of Independent Life, the other Networks of DOWN ESPAÑA have initiated incorporation processes of people with Down syndrome and intellectual disability.

Currently (2022) there are more than 50 representatives in the Networks.

Depending on the characteristics of each Network, different participation methodologies are established: Mixed commissions, advisory groups, specific meetings, etc.

Always with the objective of encouraging an active and real participation.

	INCORPORATION DOCUMENT TO THE NETWORK SERVICES' REPRESENTATIVES GROUP	Anexo I-PC-PRO 26 Revisión 05 Fecha: 12/05/2020 Página 1 de 5
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**HOW DO REPRESENTATIVES JOIN THE NATIONAL NETWORK OF INDEPENDENT LIVING?**

- 1- The National Network of Independent Living of DOWN ESPAÑA incorporates people with Down syndrome and other intellectual disabilities in their activities.
- 2- This means giving an opinion, proposing or confirming about projects, actions and materials
- 3- Each Network's entity proposes a Representative of its Independent Living services.
- 4- The proposed people form the group of Representatives of Independent Living Services
- 5- The representatives will participate in the activities of the National Network of Independent Living.
- 6- Each representative will have a reference group, which will be partners of their entity.
- 7- The representative will share with his reference group the activities he is doing in the Network.
- 8- The group of representatives will have members:
  - of different gender: men and women.
  - of different ages: youths, adults, elders,
  - of different types of disability: Down syndrome, intellectual disability
- 9- Each representative will be supported by a technician from their entity.
- 10- When an entity wishes to propose a representative it shall inform DOWN ESPAÑA.

Protocol of adhesion of representatives to the National Network of Independent Living.

## INCORPORATION OF REPRESENTATIVES INTO THE NETWORK

Representatives will participate in the activities of the National Network of Adult Life and Aging.

### **How?** As an **Advisory Body**

This means: to give an opinion, to propose, to value, to contribute on projects, actions and materials.

#### **NEXT STEPS:**

1. Each entity of the Network proposes a Representative.
2. The proposed people form the group of Representatives.
3. They will be able to be together in all the meetings they consider interesting with the professionals of the entity.
4. Some specific meetings will be held with all the representatives.
5. Each representative will have a reference group in their organization that will be made up of colleagues from their entity.
6. The representative will share with its reference group the activities he does on the Network.



Methodology for membership of representatives in the National Network of Adult Life and Aging.

## **Consultation spaces**

As established by the Committee on the Rights of Persons with Disabilities, organizations should encourage relevant consultations that guarantee a meaningful representation of the opinions, realities and needs of their beneficiaries.

This consultative spirit should be incorporated into all the organization's participation spaces.

In order to broaden the scope of representativeness of these spaces, we can implement some specific strategies such as surveys, interviews or focus groups, which may have the following objectives:

- Collect data or information that will allow a greater knowledge of the reality of people with Down syndrome.
- Collect opinions or proposals related to a specific issue of interest.
- Inform and reach consensus on plans or proposals of the organization or other bodies.

When developing these tools, we must guarantee universal cognitive accessibility criteria, such as:

- Clear and simple Information on the reason, objective and purpose of the survey.
- Informing those responsible for collecting and analysing the data.
- Define a sufficient length of the response period.
- Guarantee respect for freedom, dignity, voluntariness, privacy and data protection of any survey.
- Provide different options for physical (paper and pencil) and telematics (online questionnaire) to prevent the effect of digital divide.
- Offer support or personal assistance for people with reading and writing difficulties, upon request.
- Prioritize data collection systems that avoid or minimize the influence of third parties on the responses.

- Use simple language and clear communication criteria in the wording of the surveys.
- Limit the number and length of questions.
- Guarantee the information and return of the results to all participants.

Another way to carry out consultations is through focus groups, which select a representative sample of people who will provide information, opinions and points of view related to a matter of interest.

Focus groups are carried out through monographic meetings that must meet the criteria of universal cognitive accessibility described above, in addition to specific technical criteria:

- Define the structure of the focus group:
  - Size between 4 and 10 people.
  - Requirements of the members: age, sex, other personal characteristics, relation to the group's thematic, etc.
  - Number of group meetings.
- Guarantee support and personal assistance.
- Provide a moderator and an observer.
- Use simple language, paraphrasing to ensure understanding of information.
- Record the session to facilitate the collection and analysis of data, with prior authorization.
- Report and guarantee the information and return of the results.

**DOWN**

**Cuestionario sobre envejecimiento - personas con síndrome de Down / discapacidad intelectual**

Hola,

Este es un cuestionario para conocer un poco más sobre el envejecimiento en las personas con síndrome de Down o discapacidad intelectual.

Si tienes síndrome de Down o discapacidad intelectual y tienes 30 años o más puedes responder a este cuestionario.

En este cuestionario hay muchas preguntas. En algunas preguntas hay varias opciones de respuesta y tienes que elegir la respuesta que corresponde con tu situación. En otras preguntas tendrás que escribir tu la respuesta.

Hay preguntas sobre muchos temas, por ejemplo tu salud, tu trabajo, tu futuro...

Tus respuestas nos ayudarán a saber mucho más sobre el envejecimiento.

¡Muchas gracias por participar!

**DOWN**

**Cuestionario sobre envejecimiento - personas con síndrome de Down / discapacidad intelectual**

**Preguntas generales**

¿Cuántos años tienes? \*

Tu respuesta: \_\_\_\_\_

¿Eres hombre o mujer? \*

Hombre

Mujer

¿Te han hablado de las cosas que pasan cuando nos vamos haciendo mayores? \*

Sí

No

¿Te parece importante prepararte para la etapa de envejecimiento? \*

Sí

No

Inicio | Española | Preguntas generales | Preguntas específicas | Terminar

**DOWN**  
España

**PREGUNTAS GENERALES**

1. Tipo de discapacidad

Síndrome de Down

Otra discapacidad intelectual

2. ¿En qué país vives?

España

Otro

3. ¿Cómo se llama tu asociación?

\_\_\_\_\_

4. ¿Cuántos años tienes?

\_\_\_\_\_

5. ¿Eres hombre o mujer?

Mujer

Hombre

6. ¿Te han hablado de las cosas que pasan cuando nos vamos haciendo mayores?

Sí

No

7. ¿Te parece importante prepararte para la etapa de envejecimiento?

Sí

No

QUESTIONARIO PARA PERSONAS CON SDI

Questionnaire for people with Down syndrome and Intellectual Disability. Online and paper version.



## Other community spaces for participation

Civil society is usually organized in different space, organizations or platforms that allow the exercise of full citizenship and maximum social participation.

Some examples of civic and social participation:

- **Associations of citizens or neighbours:** represent the people from a certain neighbourhood or town. They defend the rights and interests of the neighbours.
- **Cultural, sports, leisure and free time associations:** they promote and organize cultural and sports activities, in all their experiences. They defend the values of culture and sport: painting, theatre, music, dance, literature, cinema.
- **Trade Unions:** protect the interests of workers in everything that has to do with their labour rights.
- **Political parties:** represent different interests and ideologies of the citizens, in the cities, regions or the country as a whole.
- **NGOs:** are non-profit organizations that work and defend values and activities related to human rights, equality, welfare and social development.

- **Media:** all means of communication that make possible the exchange of information in social environments:
  - Audio-visual media: television, Netflix or YouTube.
  - Radio media: example, radio, telephone.
  - Print media: newspapers, books, magazines and sending letters.
  - Digital media: newsletter, blogs, podcast, social networks, websites.

The participation of people in these spaces for citizen participation is increasing. This requires certain social and communicative skills, but also certain criteria of universal cognitive accessibility that these spaces must meet.

In the case of the media, they have style manuals that define principles and values they defend in their contents. It is important to know them in order to ensure that we are treated with dignity and in accordance to our interests and needs.

These criteria of accessibility and inclusiveness should be extended to any environment of civic participation environment.

## 1. The sustainability of our organizations rests on our active functioning as a movement of families.

The Third Sector environment in which we operate is increasingly pressing for modernization of organizations with strong legal, economic and financial requirements.

This philosophy is favoured by the European example of other countries based on a social utilitarian approach, but unstructured in the background.

However, taking the step to become professionalized structures (controlled and/or managed by professionals) is nothing more than a leap towards disappearance or loss of meaning, since:

- It falls into unequal competition with other for-profit organizations that manage services that are more likely to be able to manage more effectively.
- The *raison d'être* of our organizations is lost, especially in relation to their role as builders of social change.

## 2. Our entities are a movement of families, not only of mothers and fathers.

This means that people with Down syndrome should also be able to participate, to have presence as members, and be able to decide on the life of their Association. Around this revolves "Accessible Governance".

## 3. The participation of people with Down syndrome must be meaningful and real.

It must be meaningful and balanced with the contribution they can make. Intellectual disability exists, it is not a fiction, but it does not prevent these people from exercising their right to participate, and that the rest of us should facilitate the exercise of that right.

## 4. Our organizations must incorporate changes towards Accessible Governance, just as they are incorporating changes towards Inclusion, Transparency or ethical management.

This is another consequence of the fact of believing that the person with Down syndrome is a full human being, endowed with total dignity and with the right to participate and be part of our society.

## 5. Family members, managers and professional teams, we have the responsibility to promote this Governance and to find ways to implement it.

In the social field, what does not move forwards, takes us backwards.

In this field, it is possible to take steps forward and we only need to show willingness, courage and confidence to believe in it.



# Guide to the promotion of accessible governance



[www.sindromedown.net](http://www.sindromedown.net)  
[www.mihijodown.com](http://www.mihijodown.com)  
[www.centrodocumentaciondown.com](http://www.centrodocumentaciondown.com)  
[www.creamosinclusion.com](http://www.creamosinclusion.com)

**ANDALUCÍA:** Down Andalucía · Down Almería · Down El Ejido · Fundación Los Carriles · Down Barbate-Asiquipu · Besana-Asociación Síndrome de Down Campo de Gibraltar · Down Cádiz-Lejeune · Down Chiclana-Asodown · Cedown · Down Jerez-Aspanido Asociación · Down Jerez-Aspanido Fundación · Down Córdoba · Down Granada · Down Huelva-Aones · Down Huelva Vida Adulta · Down Jaén · Down Málaga · Down Ronda y Comarca, Asidoser · Down Sevilla y Provincia · Down 21 Sevilla **ARAGÓN:** Down Huesca · Down Zaragoza · Up & Down Zaragoza **ASTURIAS:** Down Principado de Asturias **BALEARES:** Fundación Asnimo · Down Menorca **CANARIAS:** Down Las Palmas · Down Tenerife-Trisómicos 21 **CANTABRIA:** Fundación Síndrome de Down de Cantabria **CASTILLA Y LEÓN:** Down Castilla y León · Down Ávila · Down Burgos · Down León-Amidown · Down Palencia · Down Salamanca · Down Segovia · Down Valladolid · Asociación Síndrome de Down de Zamora · Fundabem **CASTILLA LA MANCHA:** Down Castilla La Mancha · aDown Valdepeñas · Down Ciudad Real-Caminor · Down Cuenca · Down Guadalajara · Down Talavera · Down Toledo **CATALUÑA:** Coordinadora Down Catalunya · Down Sabadell-Andi · Down Girona-Astrid 21 · Down Lleida · Down Tarragona · Fundació Catalana Síndrome de Down · Fundació Projecte Aura · Fundación Talita **CEUTA:** Down Ceuta **EXTREMADURA:** Down Extremadura · Down Badajoz · Down Don Benito-Villanueva de la Serena · Down Mérida · Down Zafra · Down Cáceres · Down Plasencia **GALICIA:** Federación Down Galicia · Fundación Down Compostela · Down Coruña · Down Ferral-Teima · Down Lugo · Down Ourense · Down Pontevedra-Xuntos · Down Vigo **MADRID:** Danza Down · Fundación Aprocor · Down Tres Cantos-Sonrisas Down · Fundación Unicap · Madrid21 **MURCIA:** Águilas Down · Asido Cartagena · Asido Murcia · Fundown · Fundación SD de la Región de Murcia · Down Lorca · Down Murcia-Aynor **NAVARRA:** Down Navarra **PAÍS VASCO:** Down Araba-Isabel Orbe · Fundación Síndrome de Down del País Vasco **LA RIOJA:** Down La Rioja-Arsido **COMUNIDAD VALENCIANA:** Down Alicante · Asociación Síndrome de Down de Castellón · Fundación Síndrome de Down Castellón · Downval Treballant Junts · Extraordinarios T21

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