

FAMILY ASSOCIATIONS AND EDUCATION IN SPAIN

- THE EXPERIENCE OF PLENA INCLUSION

By Amalia San Román

Coordinator for Inclusive Education at Plena Inclusion



Where we come from...

Plena Inclusion is a family-based movement that arose in the mid 60's in Spain as a response to the needs of families with children with intellectual and developmental disabilities.

The families organised themselves into associations, led by young, fighting families, who sought the best possible alternative for their children at that time: specialised care.

They started generating "therapeutic" support and "special classrooms", where specialised professionals attended to the educational needs of their children, as an alternative to the mainstream educational system. These special classrooms started in local cultural centres or in the associations' own private premises. In a few years, families now organised as a state-wide movement, were able to arrange publicly-provided places with the Ministry of Education and create special education centres.

The demand for support throughout life led to the demand for specialised support centres for adults: occupational centres and day centres. In parallel, a multitude of services aimed at different profiles and needs were also developing such as leisure services, family support, vocational services, as well as special employment centres which were backed by a law on labour integration - aiming to respond to the need for access to employment for people with disabilities.

In the 1980s, there were already many associations that had housing resources in their communities, but the system of congregate provision of residential places in Spain meant that this more inclusive model was gradually discarded because it was seen as being more costly.

Early intervention centres for children, as we know them today, independent services coordinated with the education and health systems, came later through the recognition of their importance by the public administration in the 1990s.

Nowadays, Plena Inclusion is an association or movement that has regional organisation in its different territories, and these together coordinate a total of 950 smaller associations, foundations and entities focused on people with intellectual and developmental disabilities.

Within this movement there are more than 140,000 people with disabilities, 235,000 families, more than 40,000 professionals and 8,000 volunteers. The people with intellectual or developmental disabilities who form part of the movement are very diverse and have different characteristics: intellectual disabilities, developmental disabilities (Autism, Asperger's), cerebral palsy, Down's syndrome and experience a multitude of different situations.

The organisation all these people and entities works in two directions: the Confederation Plena Inclusion Spain is responsible for representing the interests of the movement towards the central government and ministries, as well as international bodies and social organisations of interest, while the autonomous federations negotiate directly in their territories on behalf of the entities that are part of their community. In order for this flow of actions to be coherent and aligned, the movement shares a common mission, vision and values, as well as a strategic plan that is agreed upon by all stakeholders.

Each of the associations that form part of the movement has a governing body that together form the governing bodies of their autonomous federations, which in turn make up the Confederation's state governing body.

One of the current demands promoted by the movement is the incorporation of people with intellectual disabilities in the participation and decision making of these governing bodies, as up to now they have been led by families and professionals.

Where we are going...

As we have seen in the summary of our history, we have come from generating specialised resources to respond to needs, from models based on deficits and the need to "improve" people. Now, we are moving towards models based on rights and inclusion, which support the participation and contribution of people as full citizens.

We are moving towards "ordinary lives in ordinary neighbourhoods" (to paraphrase David Towell's "An Ordinary Life" 1980). To this end, the movement is pushing for a clear strategy of deinstitutionalisation in all areas of life:

- Advocating for inclusive education, in common spaces, with support that guarantees equal opportunities.
- Supporting access to employment: promoting access to public employment, support strategies such as personalised employment, entrepreneurship, supported employment and personalised programmes for labour insertion.
- Training, occupation and leisure: supporting community approaches that generate a culture change that makes us uncomfortable with our current practices, and that encourages the pursuit of training, occupational and leisure activities in community contexts outside of specialised organisations.
- Chosen Lives: supporting new models of enabling people to live in their communities rather than in mass residential facilities, where people themselves can choose where and with whom to live through projects that demonstrate that this is not more expensive but more effective for people.
- Promoting the generalisation of the role of "Personal Assistant" as a necessary step to empower people and give them back a leading role in their lives.

In all these processes we are in a moment of "transition" from specialised models such as special education schools, special employment centres, special housing, etc. All our organisations have these types of specialised services: we are supporting gradual efforts towards approaches that guarantee access to the community with the necessary support. As in any process of transition, there is some resistance to these changes as both families and

organisations fear the loss of traditional forms of support that have taken many years to establish.

In Education...

Spain is a country that is administratively complex in relation to education policy. It does not now have a progressive and hopeful national Education Law but this is not accompanied by the budgets that would be necessary for implementation and the different territories have the power to legislate their own policies in educational matters. This makes it very difficult for us to act together at the national level.

We also find enormous internal tensions within our movement that have been magnified over the last two years with the development of this new Education Law. Within our movement, many organisations are against the inclusion of students with intellectual or developmental disabilities in ordinary schools, because in the past they have constantly experienced rejection and inadequate resources.

Our position in these tensions is mediating: we understand that many of the families that make up our movement do not want to hear about inclusion because the means to support it are still precarious (lack of training for teachers, lack of adapted resources, rigidity of the system in teaching and assessment methods, etc...) but we have a commitment to rights that ethically obliges us to demand that all public policies are provided with resources to be effective, and that progress is thereby made in the transformation of special centres.

Our conceptual framework has progressed from a model based on deficits and specific needs in highly specialised settings, towards a social model of rights, where people have the right to be, participate, learn and achieve their best in common settings, with the reasonable adjustments and personalised support necessary to promote their physical and cognitive accessibility. We have also made progress in our understanding of schools and their inclusive work. Support must accompany each student. It does not seem reasonable that it should continue to be the student who has to leave his or her immediate community environment to go to places where he or she receives the support needed for optimal development.

Inclusive education as a strategy is a cornerstone of our actions. We know that the societies of tomorrow are being built today in schools and for this reason we are committed to a calm transition process, without ruptures and with guarantees.



At Plena Inclusion we have been trying for years to contribute to this process of rethinking together i.e. with all the parties involved: families, students, professionals, community agents who are part of the schools and neighbourhoods, administrations that intervene in the processes, public and political bodies that exert forces (sometimes contradictory) in this struggle for rights. Our education project is based on the collaboration between ordinary and special schools, we know that involving both is essential for a safe advance.

In our movement, we work on three levels of impact:



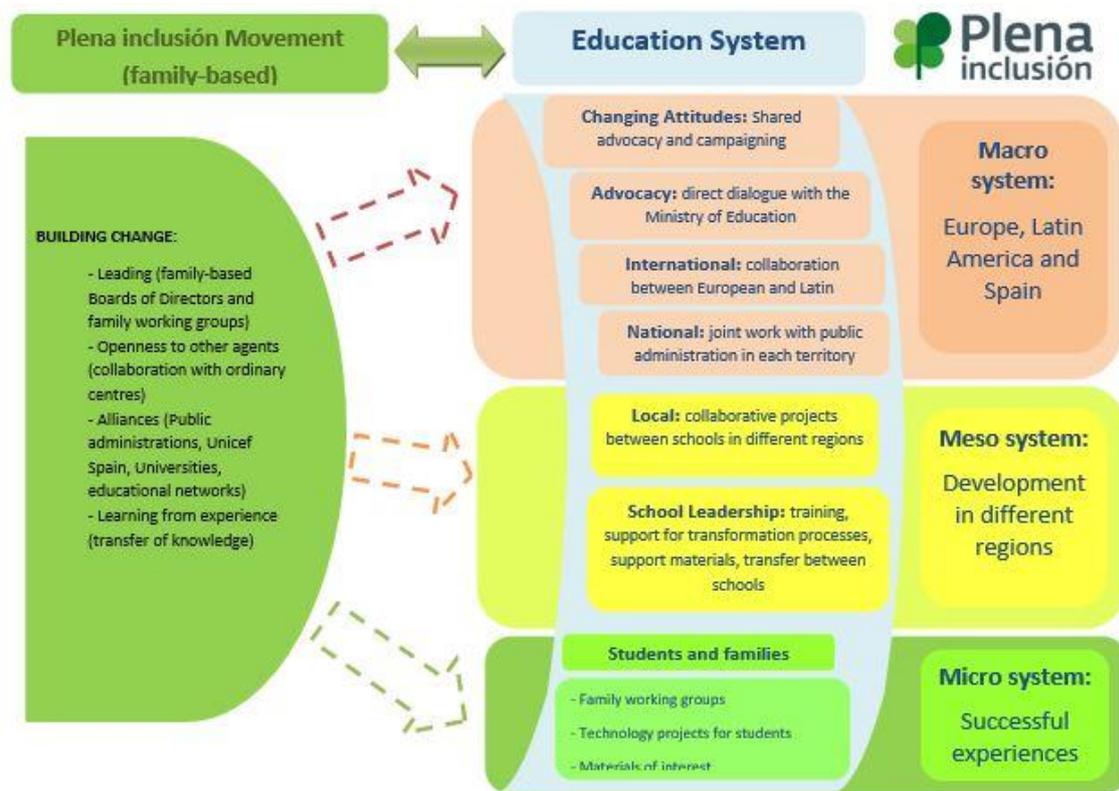
- at the macro level with the whole education community including policy makers, experts, universities, state level exchange, and international collaboration,
- at the meso level with schools and classrooms at territorial and local levels,
- at the micro level with families and students themselves,

Each of these levels engages with the education system through three fundamental lines of action:

- 1) political advocacy: political dialogue and negotiation with public administrations and policies. Our role is essential as we are very familiar with the needs of students with intellectual and developmental disabilities.
- 2) training and awareness-raising: as an opportunity to generate new cultures and practices.
- 3) the development of all kinds of resources: made available at all three levels to support progress towards more inclusive education.

These levels and lines of action combine together to create a multi-faceted strategy for delivering widespread change suggested in the diagram below.





Some of the strengths we have that are helping us to move forward are:

- collaboration with our territorial delegations through which we can reach schools;
- close relationships of trust and mutual interest with the universities that participate in our lines of research and give credibility to the results;
- alliances with other organisations aimed at supporting other vulnerable students, such as Save the Children, Plataforma de la Infancia;
- international alliances, such as Inclusion International, Inclusion Europe and EASPD, which provide us with successful experiences, learning and advocacy support; and
- an important position as key interlocutors with the public administration when it comes to legislating changes in the field of education.

The strategy for the future is to continue working at all the levels described above, working hand in hand with our organisations in their transformation, and generating "prototypes" that show examples of how these necessary changes can be developed.

Committed to an idea of our colleague Javier Tamarit: "Education is not for you, for your life, for your achievement alone... it is for you in common with others".



