



## **FAMILY ASSOCIATION STRATEGIES FOR ACHIEVING TRANSFORMATIONAL CHANGE IN EDUCATION**



**An overview of lessons from national experiences**

**David Towell**

## Introduction

Ever since families with children with intellectual disabilities first came together to share their experiences with each other and campaign for better support, education for their children has been a top priority. What are now national associations emerged in the rich countries after the Second World War (for example in New Zealand in 1949); more recently elsewhere (for example Spain in the 1960s and Colombia, 2005). Of course, over these long periods, both ideas about education and available opportunities have changed radically. In recent decades and certainly in the 21st Century, many of these associations have come to see that their children's interests are best served through their inclusion alongside other children from their local communities in schools that aspire to deliver high quality education for all: expressed more simply, in a system of *inclusive education*.

Public policy, certainly at the global level, has also moved strongly in this direction. Education is a fundamental building block in our global efforts to build a better future, a future that is sustainable and inclusive. The fourth of the 2015 United Nations Sustainable Development Goals (SDG4) expresses this challenge succinctly as being:

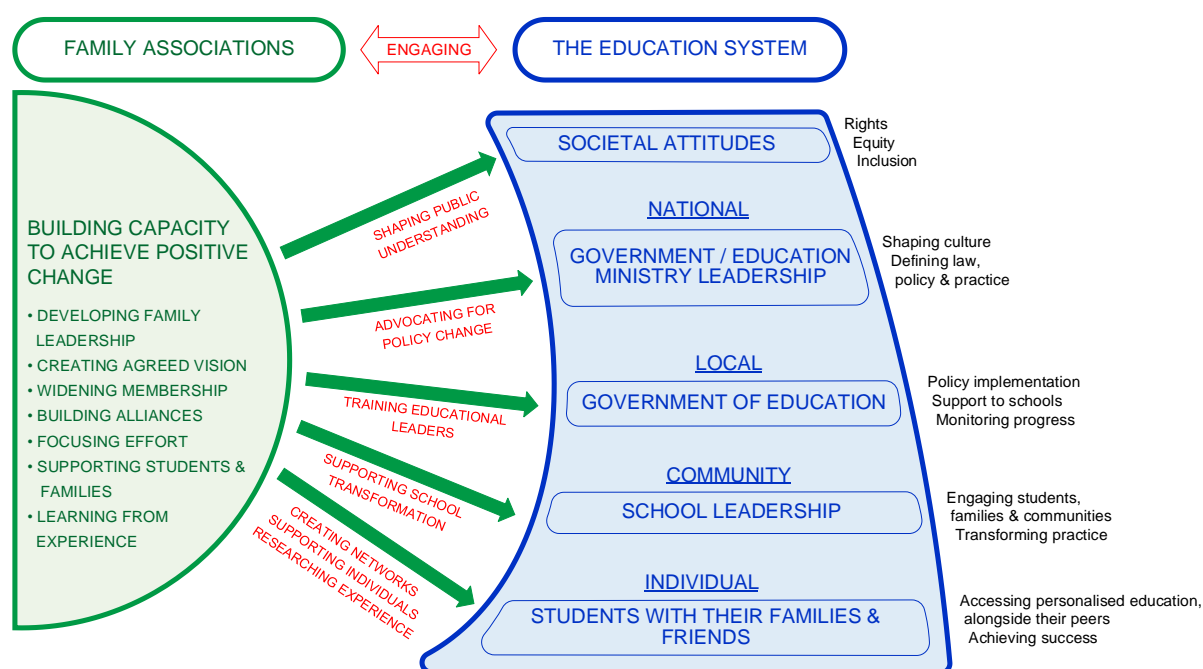
*Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all*

In this, SDG4 followed the United Nations Convention on the Rights of Persons with Disabilities (2006) that, in Article 24, calls for an inclusive system of education at all levels. However many national education systems are failing to provide quality education and there are many disadvantaged groups (economically deprived people, girls, ethnic minority including indigenous peoples, disabled people etc.) who are either excluded from education or poorly served by existing arrangements.

Accordingly, advancing quality and inclusive education remains very challenging work. Education systems are large and complex. By comparison, many national family associations addressing the rights of children and young people with intellectual disabilities are small and their membership quite dispersed. Leaders of such associations need to work hard both to build their own capacity to achieve positive change and find good ways of engaging with the education system at many levels. The diagram (below) sketches some of the most important of these interactions.

**How are family associations using their modest resources but vital experience to achieve maximum positive impact?**

## FAMILY ASSOCIATIONS AS AGENTS OF EDUCATIONAL TRANSFORMATION



At Inclusion International's Global Congress in 2018, we invited three national leaders from a diverse mix of countries (Colombia, Romania and the United Kingdom), all mothers of children with intellectual disabilities, to share their different experiences of advocating for educational transformation. Their story is published [here](#)

During 2021, we sought to build on this work by inviting leaders on education from a wider range of national family associations to share their stories. In each of the countries chosen, we know association leaders who are offering inspiring leadership to their members and productively engaged in efforts to improve public education. Of course, this has been a year when all our concerns have been dominated by the global pandemic, not least in education where most children have spent a lot of time out of school, where possible learning at home. Commonly these arrangements have magnified existing inequalities and required even greater efforts to ensure that disadvantaged children are fully included in distance education. They have also asked a lot more from parents. We are very grateful therefore to the authors who have nevertheless found time to tell their national stories.

So far we have detailed case studies from [Peru](#), [New Zealand](#), [Colombia](#) (updating the 2018 report), [Spain](#) and, thanks to Gordon Porter, the Canadian provinces of Alberta and New Brunswick (Canada is a federal country where education is primarily a provincial responsibility). These are available together on the [website](#) of Inclusive Education Canada. In this pamphlet we look across these stories to draw out key lessons that we hope will prove useful to other associations and their leaders in planning positive action.

## **Assessing the national context for educational change**

Of course, while there are many similarities in both the origins of family associations in this field and in their current aspirations, there are also significant differences in both this history and the wider context for their efforts. As we have noted, in the richer Western countries like Canada and New Zealand, family associations like those described here emerged in the early years following the Second World War. These countries (later in Spain) developed extensive Welfare States in which government took on the responsibility for funding public services and in education, providing universal services. In all three of Canada, New Zealand and Spain, the family associations themselves developed as very substantial providers of specialist services, initially in relation to education and now more often in relation to housing, day services and personal support. Accordingly, with their provider arms, these are quite large employers of professional staff and have correspondingly large budgets.

In our examples from Latin America, the history is shorter and the family associations are still predominantly advocacy and mutual aid associations. There is less publicly-funded support to families and major differences in quality and costs between public education and the large private sector provision (almost half-and-half in Peru). Indeed, while there is significant inequality in all the countries described here, these are much deeper in countries with strongly neo-liberal economic systems and major urban/rural differences. These countries vary also in the stability of their political systems (the commitment to democracy; the extent of government corruption) and in the strength of public support for civil society associations.

All these countries have ratified the United Nations Convention on the Rights of Persons with Disabilities (including its Article 24 commitment to inclusive education) but they vary in the extent that these human rights principles are reflected in domestic law and institutions. In Canada, for example, the foundational Charter of Rights and Freedoms - which long preceded the UNCRPD - offers a powerful national framework for civil society advocacy and a legal route to advancing inclusion and equity. In all of them too, there has been an evolution in both public and professional attitudes to disability, leaving them at different points in what we might think of as a journey from discrimination and segregation towards equal rights and inclusion.

In short, one key task for family association leaderships is careful assessment of the *context* for action in their countries, attending both to wider societal and policy issues and to specific features of the education system, in order to identify both challenges and opportunities for progress.

Here are twelve key questions to inform these national assessments.

## Assessing the national context

Looking broadly:

- To what extent is there national policy commitment to human rights and specifically, has the UNCRPD been ratified and expressed in domestic law?
- What is the nature of current public attitudes to diversity (i.e. in welcoming disabled people and other minorities as equal citizens)?
- How strong is the national economy and what priority is given to investment in public services?
- How far does the culture promote civil society opportunities for democratic influence?
- How far and in what ways do public authorities welcome civil society associations as partners in policy-making and service delivery?
- How strong are family and other civil society associations as advocates and change-makers?

In relation to the national education system:

- To what extent is there policy commitment to inclusive education based on a good understanding that this requires transformation in educational policies, culture and practices if all learners are to benefit?
- How far do current education policies and teacher training promote flexibility in teaching and encourage education personalised to the needs of each learner?
- Do these policy commitments embrace both public and private education?
- How far is there coherent national leadership for reform?
- How strong is international development assistance in supporting this reform?
- To what extent is education policy decentralised so as to offer local opportunities for innovation?

## From assessment to action

In achieving educational transformation, our diagram (page 3) draws attention to key elements in what are two sides to this 'equation': on the one side - building the association's capacity to achieve positive change through defining its vision and strengthening its influence; on the other side - understanding different levels in the national education system where family engagement will be required. In our diagram, the two sides are linked by the green arrows that highlight five sets of activities. Accordingly, we have analysed the case studies under seven headings to draw out pointers to association effectiveness:

## **Building association capacity**

I. Establishing an ambitious shared vision of inclusive and quality education

II. Building the association's capacity as a change agent

## **Engaging different levels in the education system**

III. Shaping societal attitudes

IV. Informing national policies

V. Encouraging local progress

VI. Promoting school transformation

VII. Supporting individual students and their families

### **I. Establishing an ambitious shared vision of inclusive and quality education**

In both public policy and in family aspirations, there has been major - and still contested - evolution in our definition of quality education and in how inclusion is understood. The British educationalist, Ken Robinson put this well (*Creative Schools* Penguin, 2016): the purpose of education is 'to enable students to understand the world around them and the talents within them so that they can become fulfilled individuals and active, compassionate citizens'. This flexible and personalised conception of quality runs counter to what is still much more common in national systems, an approach based on a set curriculum and standardised testing to demonstrate competence. Both SDG4 and the UNCRPD call for a system of inclusive education, recently defined in detail in the 2020 UNESCO Global Education Monitoring Report [Inclusion and education: All means all](#). However the [General Comment](#) on progress with Article 24 from the CRPD Monitoring Committee (2016) suggests that practice widely falls short.

On the side of families, both the New Brunswick and the Spanish case studies describe this evolution and the tensions within it well: in the latter, Amalia San Román writes that over 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.' Nevertheless in relation to education: '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.' Indeed, as the General Comment argues, the presence of, for example, disabled children in community schools is a start but not sufficient: all children need to be active participants in the educational process and achieving success, broadly defined. It has been important therefore for the national association to invest heavily in a process of rethinking education with all the parties involved, including students, as it has worked to give substance to its name, Plena Inclusión (full inclusion). Monica Cortes tells a similar story in the Colombia case study: it has been important there that families have access to positive examples of what inclusion means when it is working well as in the

experience of her own son throughout his school life. In this story, Monica also stresses the importance of learning from the best of international experience: she herself has had opportunities to make study visits to both Canada and Austria to see mature systems of inclusive schooling in practice.

Writing about Peru, Aime Apaza makes another important point. Of course, the SPSPD (Down's Syndrome Association) always starts with a focus on its own members but has come to see that advancing inclusive education for their children requires a commitment to advancing inclusive education for all young people and that difference and diversity should be recognised as opportunities not problems. Accordingly the Association in its policy advocacy work has sought to build wide alliances with other civil society groups concerned to advance education for all.

Looking across all these stories, we have identified (**Guide I**) the following pointers to establishing an ambitious shared vision for future education.

### **Guide I**

- Do we understand inclusive education simply and clearly as being the creation of learning environments that maximise the potential of every student in our diverse societies to gain a high quality education alongside their peers in local schools which serve the whole community?
- Do we define high quality as meaning that all students are not only present but also active participants in the life of the school and achieving well in relation to their own aspirations and talents?
- Do we make it clear to all partners in education that Article 24 of the UNCRPD and SDG4 require governments to ensure an inclusive *system* of education at all levels?
- Does the association leadership facilitate many opportunities for members and other allies to explore the tensions involved in educational transformation as they seek to achieve a shared view of the direction of travel?
- In discussion with parents and other stakeholders, do we have available specific examples and images of what inclusive schooling looks like in practice?
- Does the association demonstrate its willingness to learn from wide experience in testing and developing its vision of inclusive and quality education?

## **II. Building the family association's capacity as a change agent**

A compelling shared vision of quality education for all is one key element in the strength of any civil society association or network seeking to achieve transformational change. But acting on this vision requires family associations to identify and develop other assets that contribute to their capacity as change agents. Our diagram (page 3) lists seven of these.



Fundamental of course is the association membership, not just in terms of numbers of people but also what assets they bring by virtue of their family experience and other roles. The three parent leaders who contributed to the 2018 pamphlet were also respectively a teacher, lawyer and political activist: these assets shaped where they focused their own efforts. Plena Inclusión, the Spanish association, is effectively an umbrella organisation or confederation of more than 950 local and regional entities that when working together constitute a significant social movement. In New Zealand, the national association, IHC, has more than 2000 members but also works with 34 more local associations. Asdown in Colombia is a much younger association with 35 families including disabled people in its membership, based in the capital city but also working with similar small associations in 22 of Colombia's other cities.



SPSD, Peru: A cross-section of the association community

Moreover this membership strength is further reinforced in relation to education through building national and wider alliances. As noted already, SPSP in Peru has been the leading member and convener for a national alliance of organisations seeking to achieve better education for all. The Latin American associations are part of a regional network sharing experience across their continent to which Plena Inclusión also contributes. All these associations are members of the global family alliance, Inclusion International, and draw on its expertise.

Mobilising these assets requires effective leadership: building association capacity therefore requires associations to both find, nurture and support the kind of leadership relevant to action through voluntary effort and dispersed networks. In what follows we will examine what this means for action at all levels from what individual families do to get better education for their children through to how the national associations take their rightful place around the tables where policy is made.

Of course, association work across these range of levels requires financing - renting offices, recruiting professional staff, communicating with members, providing services, campaigning etc. The stories from the smaller associations in Latin America point to the importance of international support for their work and their own fund-raising: SPSP for example organises a very popular, sponsored 5k run each year. The larger associations gain most of their income from their service providing role although this mainly has to be used for exactly that. But they also use membership fees and fund-raising from supporters. **Guide II** offers some important pointers to association capacity building.



## Guide II

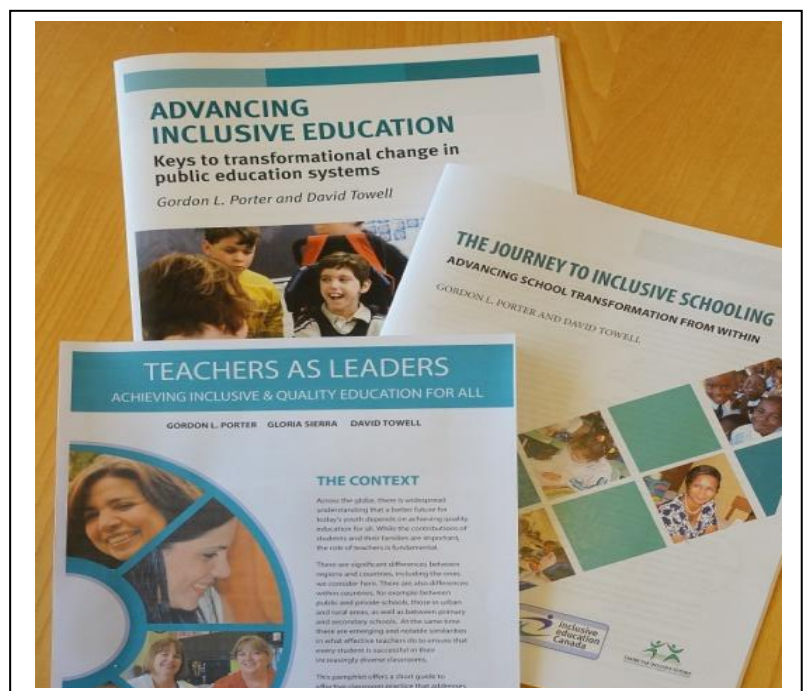
- Are we building agreement on a transformational vision of inclusive education and expressing this in simple messages to drive change?
- Are we reaching out to more families, identifying the assets network members bring to our work and strengthening our capacity to support each other and advocate for change?
- Are we building wider alliances that enhance our visibility and influence?
- Are we finding and developing the association leadership required to mobilise all our assets in the service of educational transformation?
- Are we thinking strategically about how best to focus our efforts at different levels of system change ?
- Are we raising the funds we need to support all this work effectively?

## Engaging different levels in the education system

As we have argued, transformation in education requires systemic change: indeed as Paula Hunt puts this in an important background paper ([\*Inclusive education: children with disabilities, 2020\*](#)) to the UNESCO Report, inclusive quality education for all children 'requires the rethinking and reconceptualisation of education and of ALL elements within it'.

Our diagram (page 3) describes the complexity of the education system in terms of five levels of action, from national law and policy to individual students, identifying the key tasks within the system at each of these levels.

In other work, Gordon Porter and I, working with colleagues in three continents, have sought to describe in more detail (i.e. looking at this from the side of the system itself) the requirements of transformative change at all these levels and published this analysis with many examples in three pamphlets (*Advancing Inclusive Education; The Journey To Inclusive Schooling and Teachers As Leaders*) all available on the Inclusive Education Canada [website](#).



Our case studies demonstrate ways in which the national family associations and their local allies are seeking to pursue this multi-faceted agenda in the light of an assessment of opportunities and challenges in their own country.

We use this framework to review their efforts in the five sections that follow.

### **III. Shaping societal attitudes**

Of course, education ministries themselves and the education system are embedded in the wider machinery of law and government and indeed within the society of each country and its culture. Countries differ in their attitudes to diversity and disability, in the national commitment to human rights and in political attention to advancing equality and improving universal public services.

Our case studies show that national associations understand that they must use every opportunity arising in their work to raise public awareness of the situation of their members and seek to promote positive attitudes to people perceived to be different. Monica Cortes puts this well in relation to Colombia: there has been positive legislation for more than 20 years in relation to education but practice is shaped by the 'continuing prominence of the medical model of disability' and associated assumptions about the need for 'special education'. She continues therefore that, 'we decided that the best way to change the images and prejudices that we heard from others about persons with intellectual disabilities would be to fight for their inclusion in all the spaces where their siblings without disabilities could participate. It is in school where we would make other children see them with different eyes and recognize them as persons.'

In Peru, SPSP and its local allies invest in helping new parents develop high expectations for their children - including the expectation that they will successfully participate in the life of ordinary schools - as well as facilitating the development of self-advocacy among older children and young adults with intellectual disabilities, who in turn provide positive role models of active citizenship for others.

At the societal level, these associations and even more, the much larger national associations in New Zealand and Spain, also invest in research, media and other campaigning and specific human rights advocacy directed at advancing public support for inclusion.

**Guide III** suggests some pointers to shaping public attitudes to diversity and disability.

#### **Guide III.**

- Does the association recognise the importance of public attitudes and invest in campaigning for positive change?
- Do we seek to advance human rights, equity and inclusion as core building blocks of the good society?
- Do we use every opportunity arising in our work to ensure that diversity and disability are seen as assets from which we can all learn?
- Do we work to ensure high expectations among people and families in our own membership so that they are able to demonstrate inclusion through their own lives?

## IV. Informing national policies

Our previous work ([Advancing Inclusive Education](#)) identifies eleven priorities for government level action to achieve educational transformation, in which education ministries need to exercise leadership with wider cross-government support. These priorities include legislative and other commitments to advancing rights, equity and inclusion; coherent definition of the purpose of education to benefit all students; policies that promote flexible curricula, inclusive pedagogies, assistive technologies and individualised assessment; and teacher education that prepares all teachers to respond effectively to classroom diversity.



The case studies show family associations active in seeking to influence all these activities, including through developing wider alliances with other civil society interests and teaching trade unions. The New Zealand story perhaps describes these efforts in most detail: As Trish Grant explains, over its 70-year history, IHC has researched the experience of students and families to provide an evidence base for its policy advocacy,

New Zealand: Self-advocates telling their story participated in many national forums focused on education, built wider public support through its media work and used the national human rights framework to undertake strategic litigation against the government. Similarly in Colombia, Asdown, with a much shorter history, has gained the credibility to become valued advisors within the education ministry. In Canada, the two provincial associations have a similar status at that level. Indeed the New Brunswick story in particular shows the key part New Brunswick Association for Community Living has played in that province's long and successful journey to inclusive education.

In countries where there is significant international development assistance (for example, from UNICEF) it will also be important to build partnership with these external agencies.

**Guide IV** draws together some key pointers from this experience.

### Guide IV.

In **Guides I & II**, we have already seen the importance of family associations establishing an ambitious vision of inclusive and quality education and building the capacity for strong family advocacy. In addition:

- Are we investing in systematic research to reinforce the voices of students and families in policy advocacy?
- Are we exploring multiple routes to achieving national influence including public pressure, expert advice and action through the legal system?
- Are we showing our capacity and willingness to be valued partners of education agencies at all levels?
- Are we using our expertise in the preparation of effective teachers?

## V. Encouraging local progress

In most education systems, there is a regional or local level of educational government (or both), with varying degrees of autonomy, that has responsibility for national policy implementation and should assess population needs, ensure local equity, support schools and monitor progress. Our [earlier pamphlet](#) identifies 12 priorities for action at these levels.

Accordingly, national associations typically need to work with regional and local allies to support their efforts to ensure that inclusion, equity and quality are central to action on these responsibilities. In Spain, for example, the regional level of government has considerable autonomy. In Canada, Inclusion Alberta is a regional association. In Colombia, the national association coordinates a 'Families for change network' across 22 cities. In these cases, the national and provincial associations provide advocacy tools for local leaders and training and advisory services not just for families but also for educational institutions and teachers. The case study from East London in our [2018 pamphlet](#) shows how families, working together, can exercise considerable political leadership at the level of the local education authority.

**Guide V** identifies some pointers to action at this level.

### Guide V.

- Is the national association supporting local family associations and their allies in coming together to campaign, for example at the level of the city?
- Are we helping these local alliances build effective partnerships with local education authorities?
- Are these alliances undertaking the same work locally as identified in **Guide IV** for national associations?

## VI. Promoting school transformation

Another of our pamphlets, [The Journey To Inclusive Schooling](#), examines in detail what is involved in school transformation, identifying the many elements in school improvement programmes and offering seven detailed stories from schools that have made this journey. Of course it is at this level that transformation must be demonstrated in practice. This certainly requires creative school leadership that promotes a culture in which every student feels welcome and everyone is learning; excellent support to teachers in developing flexible and person-centred teaching strategies; and real efforts to encourage family involvement in the work of the school.



Asdown, Colombia: Training workshop for teachers



The case studies show how the national and provincial family associations are contributing to addressing these requirements. Fundamentally, they are all supporting families to be well-informed partners and advocates in relation to their children's schools. They are also - like Asdown in Colombia and Plena Inclusión in Spain - developing on-line and other resources addressed to both families and teachers. The SPSPD (Peru) case study describes one interesting example of a project to support school leadership teams in advancing inclusion that included workshops that brought together multi-stakeholder teams (i.e. including school principals, teachers, parents and students) to learn from each other.



SPSPD, Peru: Inter-school learning exchange

**Guide VI** provides pointers to this work with schools.

#### **Guide VI.**

- Is the national association playing its part in developing the confidence and competence of local family networks to engage positively as partners in school improvement including through parent-to-parent support?
- Are we finding ways of encouraging school leadership for transformation including through facilitating school-to-school learning?
- Are we using our experience and resources to help prepare teachers to welcome diversity and practice effectively?

## **VII. Supporting individual students and their families**

Since we are primarily writing about, and for, national family associations, we have presented this analysis from the national level 'downwards'. However both historically and in their current work, it is more accurate to see their efforts as starting 'from the bottom upwards': transformational change begins in stories of everyday life experience. Aime Apaza, Peru, puts this well, 'Most fundamental to our work as a family association is the creation and support of family networks in which parents and other family members meet other family members to share their experiences and concerns about their children's development and inclusive education'. Our other authors all make the same point, emphasising the associations' roles in informing and empowering individual families so that

they can be effective advocates for their children and play their part in the 'team around the child'. In Alberta, this has evolved into a comprehensive family support strategy that embraces both family leadership programmes and the provision of individual advocacy support to any family that seeks this.



Developing family leadership in Alberta

Again we have a recent pamphlet, [\*Teachers As Leaders\*](#), that examines these issues from the perspectives of teachers and their classrooms. At this level teachers and families need to be partners in ensuring every student is welcome and their contributions valued in the classroom; that they access personalised education alongside their peers; and achieve success as measured in relation to their own talents and aspirations.

**Guide VII** summarises pointers towards action at this fundamental level.

#### **Guide VII.**

- Is the national association investing in creating and supporting family networks with high expectations for their children?
- Are we offering information and support to enable each family to be effective advocates for their children?
- Are we offering training opportunities that help students to become advocates for themselves, including through the involvement of older self-advocates?
- Are we researching student and family experience to provide an informed base for local and national policy advocacy?

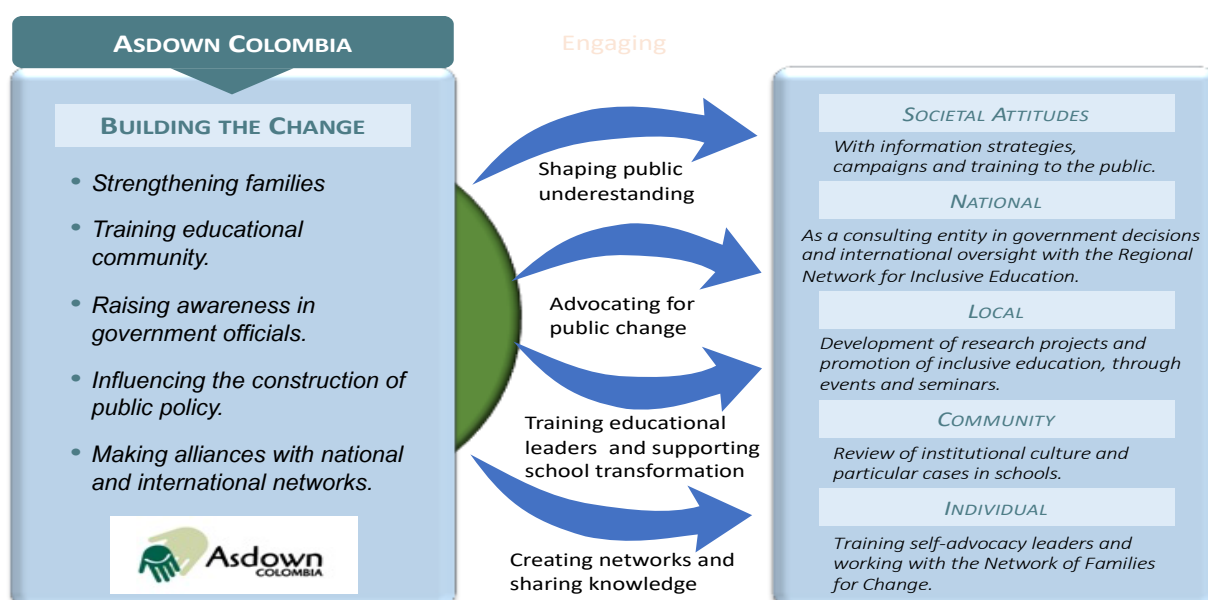
## Developing sustainable association strategies for educational transformation

Reflecting on the national case studies, this analysis has identified 30 pointers to planning what is required to advance educational system change. But association strategy requires more than a check-list. What we see in these stories is how the leadership of each association weaves together different activities along the seven dimensions we have identified in order to maximise each association's effectiveness.



Plena Inclusion, Spain: Developing association strategy

All the case studies make some use of the framework offered in our initial diagram (page 3.) Indeed some of the authors created their own versions to summarise their association strategies. This weaving is nicely illustrated in the similar diagram (below) from Asdown, Colombia.





We have seen that association strategy needs to be:

- ✓ grounded in an appreciation of opportunities and challenges in the wider context for educational change;
- ✓ built on a clear vision of inclusive education;
- ✓ pursued in the light of an assessment of strengths and limitations in the association's own assets in relation to influencing change at all levels from the individual learner to national law and policy;
- ✓ aiming to engage students, families, teachers, policy-makers and other stakeholders in the education system;
- ✓ shaped by an understanding of key elements in the system of education required to support the vision and an appreciation of which of these elements are most in need of change;
- ✓ developed with attention to the tensions that arise, for example in locating the needs of disabled children in the context of other kinds of diversity and managing the shift from 'special education' towards full participation in mainstream provision; and
- ✓ continually updated in the light of progress (or otherwise) in the strategy and learning from the experience of students and families.

What our stories also show is that this work is a journey, never entirely completed: even in the countries where most progress has been made towards achieving SDG4, family associations continue to strive to better ensure inclusive and quality education for all.

We hope both the national stories and this comparative analysis will be a valuable resource to national associations and their allies in other countries in continuing this work. At all levels, including the regional and global, we can best make progress by networking with others and learning from our collective experience. Accordingly we hope that this analysis will stimulate national leaders elsewhere to share their stories.

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