FAMILIES AS LEADERS IN THE JOURNEY TO INCLUSIVE SCHOOLING

Keys to achieving transformational change

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I. **Overview**

Inclusive education has two main goals: To ensure the right of every young person to a quality education and to help build communities that benefit everyone. Stated simply, by inclusive education we mean the creation of learning environments that maximise the potential of every young person to receive a high quality education alongside their peers in local schools which serve the whole community. Inclusion helps all children prepare to live and thrive in our ever more diverse societies.

An important dimension of this diversity relates to disability. The right of disabled children to receive an inclusive education has been most forcefully expressed in Article 24 of the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD) which calls unequivocally on governments to 'ensure an inclusive system of education at all levels'. Rather more than 170 countries have ratified this Convention but sadly, in most jurisdictions, ratification does not necessarily mean delivery. The recent (2016) UN General Comment (1) on progress in implementing this Article points to widespread misunderstandings and shortfalls.

Indeed our experience as family members in three rather different countries - and what we know from elsewhere - tells us that for most families with disabled children, gaining and sustaining access for our children to quality education in mainstream schools remains a continuing struggle, even where legislation suggests it should be otherwise.

Of course, transforming public education (2) to achieve full inclusion requires major effort from policy-makers, school directors and teachers, among others. We also know that this transformation is only likely to be achieved where families, their networks and more formal associations are strong advocates for inclusion and partners with the education system in delivering fundamental change at all levels from the classroom to the education ministry.

This pamphlet is addressed to parents with disabled children and their siblings taking up *leadership roles* in advancing the journey towards inclusive schooling. Three of us are mothers of children assessed to have intellectual disabilities (the terminology preferred in the U.K. is 'learning disabilities'): we started by campaigning for our own children's education and found ourselves with significant roles in wider family networks concerned to make education better for everyone. *We know that if inclusive education is going to become a reality, policymakers and schools must understand what families are thinking.*

Here, the three of us as mothers tell a little of our own story. Of course we have rich personal accounts of the struggles we and our children have made, and are making to live their lives to the full. There is both much joy and many tears in these stories. But we focus here on the work we have done in association with our allies to improve education for *all* children.

Monica Cortes is Executive Director of the national association, Asdown, in Colombia. She tells the story of the development of this association over the past 12 years and their efforts to go beyond mutual aid among families, both to help families understand better the merits of inclusive education and to gain a voice at the tables where policies are made.

Madalina Turza is Executive Director of the European Centre for the Rights of Children with Disabilities (CEDCD), based in Romania. In her country there is still widespread discrimination against disabled people, segregation and abuse. CEDCD has pursued legal routes to establishing their human rights and mobilised a grass-roots movement campaigning for fundamental change.

Linda Jordan works for a national development agency in the U.K. focused on advancing inclusion. She tells the story of how she and other highly committed parents in the London Borough of Newham used political activism to transform local education, closing 'special schools' and investing instead in universal mainstream schooling.

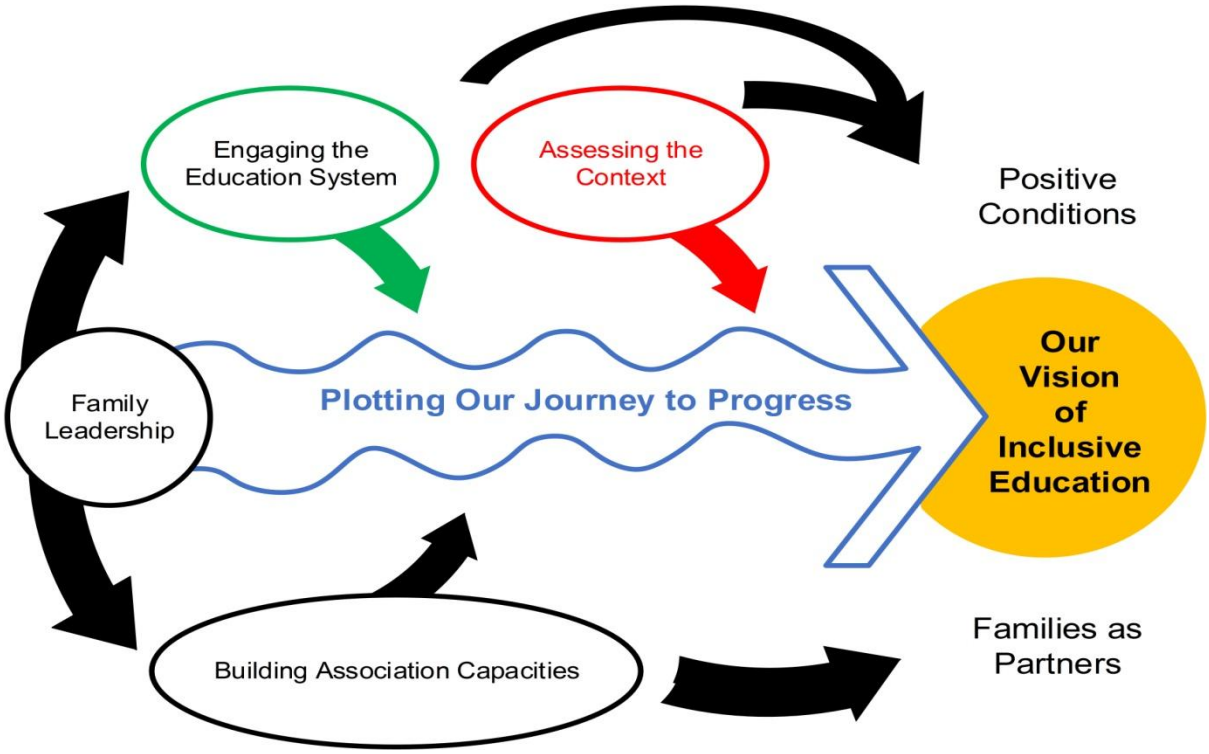
As we discuss in more detail in what follows, these three countries are of course different in many ways. We shall be exploring how family association strategies need to be shaped to take account of these differences.

The fourth author, **David Towell**, had an older sister with profound disabilities and now directs the London-based Centre for Inclusive Futures. He has worked with family leaders in all three countries. The four of us have joined together in seeking to draw lessons from our different national experiences.

In addition to sharing our experiences with other family association leaders, our aim in this pamphlet is to help identify the strategies family leaders and their associations need to adopt in order to advance the journey to inclusive education in their own countries, taking account of different local and national circumstances.

We summarise these lessons in the form of *keys to achieving transformational change* (illustrated in the diagram below). Five seem most important.

First, networks and associations of families need to develop their own capacities to be effective. Marshall Ganz (3) has written a great book about the struggles which originally gave rise to President Obama's campaign slogan *Yes We Can!* under the title *Why David Sometimes Wins* (in battles with Goliaths). We have to see ourselves as change agents: establishing a clear vision, identifying and amplifying our membership and its assets and focusing our efforts where these will have most impact.



Second this vision for inclusive education must be ambitious, seeking to ensure that *all* students are not only present but active participants in the life of local schools and achieving well in relation to their own aspirations and talents: that is, firmly grounded in *Article 24* of the UNCRPD.

Third, we need to follow *Article 24* in seeing that achieving this vision requires radical change in educational *systems* so that every school is supported in this transformation and inclusion becomes an intrinsic feature of policy, culture and practice from the classroom to the education ministry and a core expectation of the communities in which schools are embedded. This means campaigning, among other things, for a holistic appreciation of education as *education for life*, for committed government leadership and proper investment in equity and quality, for appropriate reforms in professional education, for active attention to removing the barriers to student participation and for the creative development of inclusive pedagogies.

Fourth, every jurisdiction is, of course, different. Taking, for example, the three countries where Monica, Madalina and Linda exercise leadership, there are differences in national policy commitment to human rights, the opportunities for democratic influence and whether public institutions welcome civil society associations as partners. There are also differences in public attitudes to disability, the coherence in governmental leadership in education and the flexibility or otherwise of traditional teaching methods. And our family associations differ in the size of their memberships, past experiences and current skills in campaigning. Clearly family association strategies for educational change need to be informed by

a careful assessment of the opportunities and constraints shaped by all these factors.

Fifth therefore, every family association, whether working locally, nationally or both, needs to plot its own pathways to achieving progress with attention to all four of the preceding themes ....and continually update these pathways in the light of experience.

Families and their associations need to prepare themselves for a long journey, always keeping in mind that *David Sometimes Wins*!

II. Three Stories From International Experience

Colombia: Building the family association

Colombia is a large and beautiful South American country with nearly 50 million population. It is also a country with major inequalities between rich and poor, urban and rural areas - and lives with the damage arising from 50 years of civil war, including 6 million displaced people mainly resident around the edges of the major cities. In relation to inclusion, there is some helpful legislation but also many traditional attitudes.

Monica writes: My name is Monica Cortes, I'm a teacher, I worked for 16 years in schools here in my country and I have two sons, my older son Alejandro is 18 and he was born with Down's syndrome. For that reason I started to prepare myself in all the different aspects related with Down's syndrome. I also began a family group that wanted to find out how to help other families who had sons and daughters with intellectual disability and I learnt about their rights to be included in the society.

In 2005 we created Asdown Colombia, a family organization with the principal objective of promoting the rights and the inclusion in our society of all persons with intellectual disability. So we started to work supporting families, promoting inclusive education and practicing advocacy in political places, because we understood that we needed to be there saying that our children, young people and adults also are persons that have rights. We have also worked to promote the growth of self advocacy in Colombia.

Since 2008, we became a member of Inclusion International and we started as a family organization to receive very important support in knowledge about the topics that have most impact in the lives of persons with intellectual disabilities and their families, related to their rights and inclusion in the society (4).

One of the most important things that I have done since 2011 has been to be elected (twice) to represent persons with intellectual disability and their families in the National Council of Disability. In this place I have learnt about how I could make effective advocacy to defend the rights of persons with intellectual disability and how we could change laws to include our people in all policies and programs that the government is developing.

Another activity that I coordinate since 2010 is the *Families for the Change Net*, a group of family organizations and leaders that work in 22 cities in Colombia promoting the rights of persons with intellectual disabilities.

I consider that joining our voices is the only way to gain the strength to change the world for people with disabilities. In this network we have worked to achieve a common vision of what is inclusive education; we analyze the experiences that families face to get their sons and daughters included in the regular school system in different cities and we try to give tools (e.g. relating to the laws defining the right to be included in regular education) to the leaders in order that they can give good support to other families.

Our country situation

In Colombia since 1997 we have had wide legislation that recognizes the right to education for all persons with disabilities but there remains a big problem in changing attitudes in relation to mainstream educational participation (and also in the large private education sector) because of the continuing predominance of the 'medical model' of disability, with the consequence that teachers believe students with disabilities need special teachers and therapy and school leaders continue to practice discrimination against disabled people.

Similarly, families consider that the regular schools aren't well-prepared for disabled children and so they need special education. But I consider that we have taken good steps, because the government doesn't accept segregated foundations or schools as an option for students with disabilities and in the last 5 years we have new laws and guidelines to implement the mandate of the UNCRPD.

Since 2008, Asdown Colombia has worked to promote different actions to contribute to progress in inclusive education. We started with research about the status of inclusive education in Colombia, with UN Voluntary Fund resources and with support from Inclusion International. We organized teacher seminars with expert training about inclusive education and we visited the inclusive education models in Graz, Austria and in New Brunswick, Canada, and found different good practices from teachers and schools in Colombia, to build our knowledge about inclusive education systems. We started to be considered by the Ministry of Education as experts and we started to work as advisors on different topics concerned with inclusive education for students with intellectual disabilities, for example in designing new laws, training for teachers and

guidance on working with families. Since 2015, Asdown has also belonged to a Regional Net (5) for inclusive education with 8 other Latin American countries and we have the opportunity to share good experiences.

Our experience in inclusive education

In my case, my son has participated in regular school during all his life and next year he is going to graduate to high school level, so it's a wonderful achievement. I have had to learn a lot about how to encourage teachers to understand what is the best way to help my son learn. I have had the advantage that I am a teacher, but of course I myself had to learn about how Alejandro learns and what are the best ways of developing his abilities.

But it's not the same for all families, because few disabled children continue education beyond primary school. Our whole system struggles with introducing flexible curricula and universal design for learning.

Our strategies looking forward

There is much more work we need to do with families so that they have what they need to demand the right to inclusive education for their children. Looking forward, we need to continue developing campaigns to change public perceptions of disability and to promote inclusive education, ensuring that all the education community understands that this will be a better education for all.

It's necessary to develop good teacher training because our teachers have been taught within the assumptions of the medical model, but not in the idea that all children can learn irrespective of their labels: teachers need appropriate strategies to teach everyone within the framework of the same broad curriculum.

Romania: Legal advocacy for human rights

Romania, population 19 million in the East of Europe, is a very challenging context for advancing inclusion. Traditional medical views of disability prevail. Institutions and segregated special school are still in place. Thousands of children with disabilities are either abused in institutions or isolated in families and lack any community services. Out of the total number of school aged children with disabilities (estimated at 60,645), over 30,000 are segregated in special schools and 17,975 children are out of school.

The political culture is authoritarian - civil society associations are regarded with suspicion - and local community organising is weak, a consequence of a long period of centralised dictatorship.

Madalina writes: I am a disability rights advocate with a legal background and I have a wonderful daughter with Down's syndrome, Clara. She is 13 years old. Nine years ago, I realized that if I don't stand up for my daughter nobody will. So, I decided to become a Parent Advocate. With just a laptop, a car and my law and human rights knowledge I started the most important struggle of my life: the struggle for inclusion and equal rights for our children.

I created from scratch an organization, European Center for the Rights of Children with Disabilities (CEDCD), fighting for the rights of children with disabilities before the Romanian courts. I travelled across the country to reach the many thousands of parents at the end of hope. I created a coalition of parents. We drafted a bill, we marched on the streets both night and day. I have tried to reinvent strength and hope in the potential of our children. The struggle is not over, but I do believe that PARENTS are the key to real and effective change.

As we see above, the situation of children and adults with disabilities in Romania is very precarious. Legislation in the field of education for children with disabilities is extremely complicated, generating confusion and lack of trust among children with disabilities and their parents. The current setup involves multiple state agencies subordinated to different ministries, and to local and central authorities respectively, and parallel and overlapping evaluation and monitoring procedures, which however are not meaningfully implemented.

During the preschool period, children with disabilities do not benefit from adequate early intervention services, parents being forced to spend large amounts of money to access these services in the private sector. Children often must travel long distances to attend special schools, particularly those living in rural communities. For this reason, many children with disabilities from poor families end up being institutionalized in boarding schools.

Evidence has recently come to the attention of the public suggesting that high rates of physical abuse occur in special schools, and that sedation is used as a method of managing children perceived as troublesome. As for my daughter, Clara, since she was denied access to a mainstream school, five years ago, I enrolled her in a special school in Bucharest. In January 2014, she suffered from verbal and physical abuse perpetrated by a teacher, as documented in a medical certificate and post-traumatic psychological reports. We filed an administrative complaint with the Bucharest School Inspectorate and a criminal complaint. After a three-day investigation, the School Inspectorate dismissed the complaint as unfounded. The criminal complaint was dismissed too after several years, at the Romanian Supreme Court.

Our vision and strategy

CEDCD grew as an organization with a legal profile, providing legal counselling and representation for the parents and children with disabilities before the courts. This is how, in a very short period of time we succeeded in reaching thousands of parents nationwide and increasingly understood that one of the most problematic issues when it comes to children with disabilities is access to quality education.

When I founded the CEDCD, children with disabilities were accepted in mainstream public schools only as a matter of exception. Too few children with very mild disabilities were accepted by teachers and school principals and usually based on a personal relationship with the parents. My priority was to bring together a team of legal practitioners and lawyers to litigate for the right to education of children with disabilities. In nine years of activity, I personally provided legal counselling for more than 800 parents. I publicised each case of discrimination, abuse or victory before the Equality Body or the courts through press releases, interviews, TV debates and constant online communication using social media. After years of litigation and no case lost on this subject, the Romanian Ministry of Education issued an internal regulation prohibiting restriction of access to mainstream schools of children with disabilities, although this was most of the time not respected. However, in 2016, we succeeded in changing a small secondary legislative provision that allowed parents to choose the type of school they want for their children: segregated or mainstream. Although no measures of support and accessibility were taken to ensure quality education for children with disabilities, the denial of access to mainstream schools by the teachers and directors decreased significantly. And this represent a first important step towards inclusion in education - “formal access to education ensured”.

In view of the general situation of children with disabilities in Romania, particularly with respect to the right to education, we understood that the only way in which comprehensive change could be achieved was by developing a strategy for systemic reform. We started a large voluntary-based campaign to promote the adoption of a new law on the rights of children with disabilities in Romania, in line with the UNCRPD.

In 2013 we established the first national coalition of grassroots organizations of parents of children with disabilities. We organized regional debates across Romania, expert working groups, public marches and raised almost 35,000 written and online signatures supporting the new draft law.

One of the specifics of our grass-roots organization of parents is the creation of a strong online national community that enables us to communicate in real time, to convey relevant and urgent information to parents, to send action alerts and to mobilize the most active ones when it comes to having an official position towards a public issue. In the context of the lack of local community engagement, we found this alternative way of building solidarity and communication between parents.

However, we do hope for the revival of local community engagement and we encourage local initiatives by supporting emerging parent leaders through training and direct participation in our events.

Despite the fact that the draft law is still pending approval, with no real chances of success, the processes that generated this large grass-roots movement seem to be making an impact. Besides the parents who are taking steps towards a coherent voice for inclusive education, there is rising support elsewhere for our demands. It seems that the teachers in mainstream schools are now being confronted with large number of children with disabilities in their classrooms given the “parent-choice” provision. So they too have started to advocate within the system for adequate learning facilities, specialty training and a flexible curriculum.

This struggle is, however, at its early stages. Parents still need empowerment and leadership skills, teachers still need training and encouragement to implement inclusive measures in schools and the society at large still needs a shift in mentality and perception.

United Kingdom: Local activism to deliver education system transformation

The United Kingdom is an economically rich country on the Western edge of Europe, population 66 million. Despite more than 40 years of permissive or supportive legislation, there remains significant reliance on special schools which segregate children with disabilities. Newham (with a highly diverse population of 310 thousand) is a relatively very poor borough in the East of London.

Linda writes: My story begins in the 1980s. The 1981 Education Act introduced a new system covering the education of children with special educational needs. The Act said that children should be included in mainstream schools “where appropriate”.

We live in Newham, where my beautiful daughter, Ellen, was born in 1982. Immediately we were confronted with a barrage of negative messages because she had Down’s syndrome. The worst was the local community paediatrician telling us that children with Down’s syndrome do not learn beyond the age of 7 and that all this talk about inclusion was “rubbish”. By amazing good fortune there was a very active local parent support group which had started to talk about the implications of the 1981 Act. We got involved and the whole group made a pact that all of our children would go to their local mainstream schools and that we would support each other to achieve this.

We met the local Chair of the Education Committee and the Director of Education to ask them how they were going to respond to the inclusion requirements of the 1981 Act. They were fairly positive and set up a “working party” to develop a local policy. The working party was to include 4 parents and they asked our group to nominate people, which we did. I was one of the 4 parent representatives on the group. The group met for 18 months and meetings were not easy.

At the end of the life of the working party, there was not a consensus. The main report of the group promoted more inclusion but took a very gradual and cautious approach. The parents and one other (a teacher representative) produced “Report B” as an alternative. Report B set out a simple but radical approach to closing special schools and transferring the resources to mainstream schools. Both reports went to the Education Committee and the Committee sent the officials away to come back with one report which amalgamated both.

By now it was late 1985 and local Council elections were going to be held in May 1986. I was persuaded to stand for election to the Council which I did and I was elected. I became Chair of the Education Committee and took a policy statement to a meeting of all councillors.

The policy statement was unanimously agreed and we started work on turning the policy statement into a strategy.

The first step was that all young children starting nursery would go to their local nursery. We set up a pre-school teaching team who then supported each nursery to include children and as more children were included, we increased the size of the team until it could support children and young people of all ages.

We closed six special schools in six years and all of the resources transferred to support children in mainstream schools. When we were planning to close a school we worked very closely with parents. We ran workshops and asked people what they would desire for their children “in an ideal world” and they were very much involved in the planning of the new provision. We involved the children in the discussions. It was also important that we were linked to other networks of parents and like-minded professionals across the country as this added to our strength.

Some parents whose children attended special schools were worried about their child being placed in a new school where they would not have friends and where the teachers may not understand their disability. We decided to set up some “resourced schools” which meant that some children could go from the special school to the same mainstream school together. Resourced schools develop expertise around a particular disability. One primary and one secondary school were resourced to make provision for deaf children. This meant that there were interpreters, teachers of the deaf and facilitators. All children in the schools learned sign language. Another two schools were resourced to support children with complex autism and another two for children with profound and multiple disabilities. Most of the children from the special schools went to their local mainstream schools but it was important to be flexible and respond to the concerns of parents – as long as the result was that children were included.

Newham continues to be the most inclusive local area in England, and some others have made great strides towards inclusion.

During the last fifteen years British governments have moved to the right and education has suffered. We now have an elitist model which concentrates on the “most able” and pretends that if a child works hard they can be socially mobile and get into a “good” university. The curriculum has been narrowed, children are taught in groups based on levels of ability and the arts have been squeezed. Nationally, there have been many casualties. The number of children excluded from school is at an all-time high and many children are moved to “alternative provision”. The number of children placed in special school has also risen. Many parents across the UK are still campaigning hard for inclusion but of course others are intimidated and bullied into thinking that inclusive education cannot work. It is important that we keep showing fantastic examples, highlighting that discrimination is illegal and that inclusion is critical to the health of society.

Inclusion remains on the agenda. The majority of people I meet and talk to realise that one day all children will learn together as it is clearly the right thing to do. It is important that we continue to expose the evil of segregation in all of its forms and show how everyone benefits from understanding that we are all different and that we all have different needs for support but that ultimately we are all human and have equal value.

I want all disabled children and young people to enjoy the benefits of inclusion that my daughter has. She is now 35 and has a fantastic life. She lives in her own flat with a friend, travels around London on the complicated transport system, she works and has a great social life. When she was a baby, I used to say that I didn't care whether she learned to read and write but that I wanted her to be included in her community and have friends who cared about her. She certainly has that but also having had a proper education has shown that people with learning disabilities have been denied their rights for too long and that with great teachers who believe in equality, people can learn so much more.

III. Five Keys To Achieving Transformational Change

Introduction

To repeat, these three stories illustrate how family leaders, our associations and networks need to find their own pathways to advancing inclusive education, grounded in an understanding of UNCRPD Article 24 and an assessment of local and national opportunities and barriers. Reflecting on these and other stories with David Towell, we try here to draw out some general lessons for creating effective change strategies, expressed in five 'thinking tools'. Our hope is that these five tools will be useful to other family leaders and associations in planning positive action in their situation.

In relation to each tool, we highlight some things from the previous stories which illustrate what we have in mind.

1. Building the capacities of family associations as change agents

In each of our stories, we can see how the experiences of our own disabled children, good and bad, drove us towards leadership roles in family movements for change. Moreover our different personal talents, for example respectively as teacher, lawyer and political activist - and the networks to which these talents gave us access - were important in shaping our approaches to securing change in education. In all our stories too, an essential step was reaching out to other motivated families and extending supportive networks among parents. So, an important part of building the capacities of family associations is identifying the assets members bring by virtue of their experiences, expertise and personal networks.

In all our stories too, it has been important for family members to come together to develop a clear view of what we want for our children and to back each other up in seeking to achieve this. In Newham, a core group of local families made a pact that they would all seek mainstream schooling for their own children. In Colombia, Asdown is seeking to show all parents the benefits of inclusive education, done well. In Romania, Madalina and her associates have made the defence of human rights central to family strategies.

The system level focus of these efforts has responded to the nature of the challenges. In Romania, the legal path has been taken in relation to a large number of individual children at risk of exclusion and worse. At the same time, law change has put more power in the hands of parents and increased pressure for change within schools. In Newham, Linda and her allies gained the political authority to lead radical change in the local school system. In Colombia, Asdown has developed the

capacity to play a part not only in national policy-making but also in providing training to teachers.

We offer the following points for reflection on building family association capacities:

Developing the capacity of family associations to advance inclusive education requires association leaderships to address and link three sets of questions:

- Setting clear direction – Are we building agreement on a coherent and transformational vision of inclusive education and expressing this in a simple message to drive change?
- Strengthening association capacity – Are we reaching out to more families, identifying the assets network members bring to our work, making alliances and strengthening our capacity to support each other and advocate for change?
- Thinking strategically about how best to focus our efforts at different levels of system change -

- Are we organising around individual families to support their efforts to secure quality inclusive education for their children?
- Are we establishing partnerships with individual schools to inform and assist their efforts at transformational change?
- Are we engaging productively with the education system to use the opportunities and overcome the barriers to policy reform?

2. Establishing an ambitious vision of inclusive education

In countries like Colombia and the United Kingdom where national legislation already offers some commitment to inclusive education, our stories show that family associations still need to find ways of defining what this means, for example at the level of the school. The presence of disabled children in mainstream schools is a start but not sufficient: all children need also to be active participants in the educational process and broadly achieving success. Equally, many families with disabled children learn from experience to have low expectations of public education: in all our countries it has been important to offer fresh hope to parents based on a human rights approach to our children's education.

Of course this is easier to achieve when we have access to positive examples of what an inclusive system looks like. In our stories, Monica's son and Linda's daughter were able to demonstrate inclusion in their own school experience. Actually, so did Clara, Madalina's daughter, but not until Madalina had a year's scholarship in the USA and

Clara was welcomed to a mainstream school there. (Ironically Clara was welcome in the USA while not speaking English but excluded from school entirely in Romania after her abuse in a 'special school'.) All three mothers have had the opportunity to visit other countries and see inclusive education in practice. Monica, for example, has undertaken two study visits with Latin American colleagues to New Brunswick in Canada, one of the few jurisdictions in the world which has a long established comprehensive system of inclusive education. (See Note 3.) Of course not everyone can travel widely but there is a wealth of excellent illustrations available on the web (6).

What these examples have shown us is that the weaknesses in many places identified in the UN General Comment (See Note 2) can only be avoided where we see inclusive education in the school as dependent on transformation in the whole educational system.

We offer the following points for reflection on establishing an ambitious vision:

- Do we understand inclusive education simply and clearly as being the creation of learning environments which 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?
- In discussion with parents and other stakeholders, do we have available specific examples and images of what inclusive schooling looks like in practice?
- Do we make it clear to all partners in education that Article 24 of the UNCRPD requires governments to ensure an inclusive *system* of education at all levels?

3. Engaging relevant elements in the national *system* of education

In all three of our stories, family leaders recognised that while our associations need to find ways of helping each child and each family seeking better education, success for many children requires multi-faceted strategies for systemic reform. And as the Romania story shows us, the more difficult the current situation of disabled children and their families, the more radical and far-reaching are the nature of these reforms.

Multi-faceted means addressing different stakeholders - other parents, students, teachers and policy-makers, but also political associations, trade unions and other civil society associations - and working at different levels: schools of course but also local administrative bodies and national laws and policies. Law change in Romania

has promoted inclusive expectations and produced new pressure on the schools. The Newham story offers a detailed account of local policy innovation and its implementation. In Colombia, an important focus of Asdown's efforts has been on changing teacher attitudes and spreading knowledge about flexible curricula and universal design for learning.

In all three countries, family associations have played a role in assessing the need for change and ensuring that public policy and practice learn from the experience of children and families.

We offer the following points for reflection on engaging with the national system:

Is there widespread recognition that delivering a positive vision of inclusive education requires that inclusion becomes an intrinsic feature of policy, culture and practice from the classroom to the education ministry and a core expectation of the communities in which schools are embedded? Is attention being directed towards ensuring that:

- Policy-makers, teachers, families and learners develop a *shared understanding* of what inclusive education is?
- The *purpose* of education is understood as preparing every student to live their own life to the full and build an inclusive society?
- There is a nation-wide commitment to *equitable access to quality education* based on recognition that inclusive education is a fundamental human right of all learners?
- Government nationally and locally *invests resources* to achieve equity and quality in relation to population need and monitor student educational achievement?
- There is widespread investment in developing and supporting *leaders* capable of both inspiring and managing the transformations in thinking and practice required by inclusion?
- This transformation can only successfully be delivered through *partnership* among policy-makers, school principals, teachers, families and students, including support to the development of family associations with the capacity for mutual support and advocacy?
- Teachers in particular require that both pre-service and continuing *professional education* fully equip them for inclusive classroom practice?
- At all levels, policy and leadership must address the attitudinal, physical and material *barriers* to student participation in their local schools?

Continued:

- Inclusive education requires advancing *inclusive pedagogies* for example: universal design for learning, flexible curricula, personalised learning plans and classroom assistance?
- The journey to inclusive education is a voyage of discovery: this transformation needs continuing efforts to *learn from experience* as the journey proceeds?

4. Assessing opportunities and challenges in the wider context for educational reform

Just as schools are embedded within the wider education system, educational reform is in turn affected by wider issues in the society and economy. Our stories show some of the ways our family associations have sought to take account of these issues in promoting positive change.

All our countries make human rights commitments and espouse democracy but the extent to which either of these things are realised in practice varies. In Romania, Madalina and her colleagues have been required to campaign and make legal challenges from the 'outside' in order to shift public policy. In Colombia, Monica has been invited inside policy influencing processes. In the U.K., where there is extensive decentralisation in education policy-making, Linda and her colleagues were able to become the policy-makers in Newham through using local democracy.

In our countries there are differences too in the extent of segregated education, the availability of private sector schooling and the priority given to 'academic' success in public education. We have had to adapt to these realities in seeking to ensure inclusive education for all.

We offer the following points for reflection in assessing the wider context for reform:

Are family association strategies to advance inclusive education through educational system transformation carefully assessing opportunities and challenges in the wider context, for achieving change?

Do these assessments attend, for example, to:

- The extent of policy commitment to human rights, including whether the UNCRPD has been ratified and expressed in law?
- National economic strength and the priority given to public services?
- The extent of civil society opportunities for democratic influence?
- How far public authorities welcome civil society associations as partners in policy-making and delivery?

Continued:

With specific reference to education, assessments also attend, for example, to:

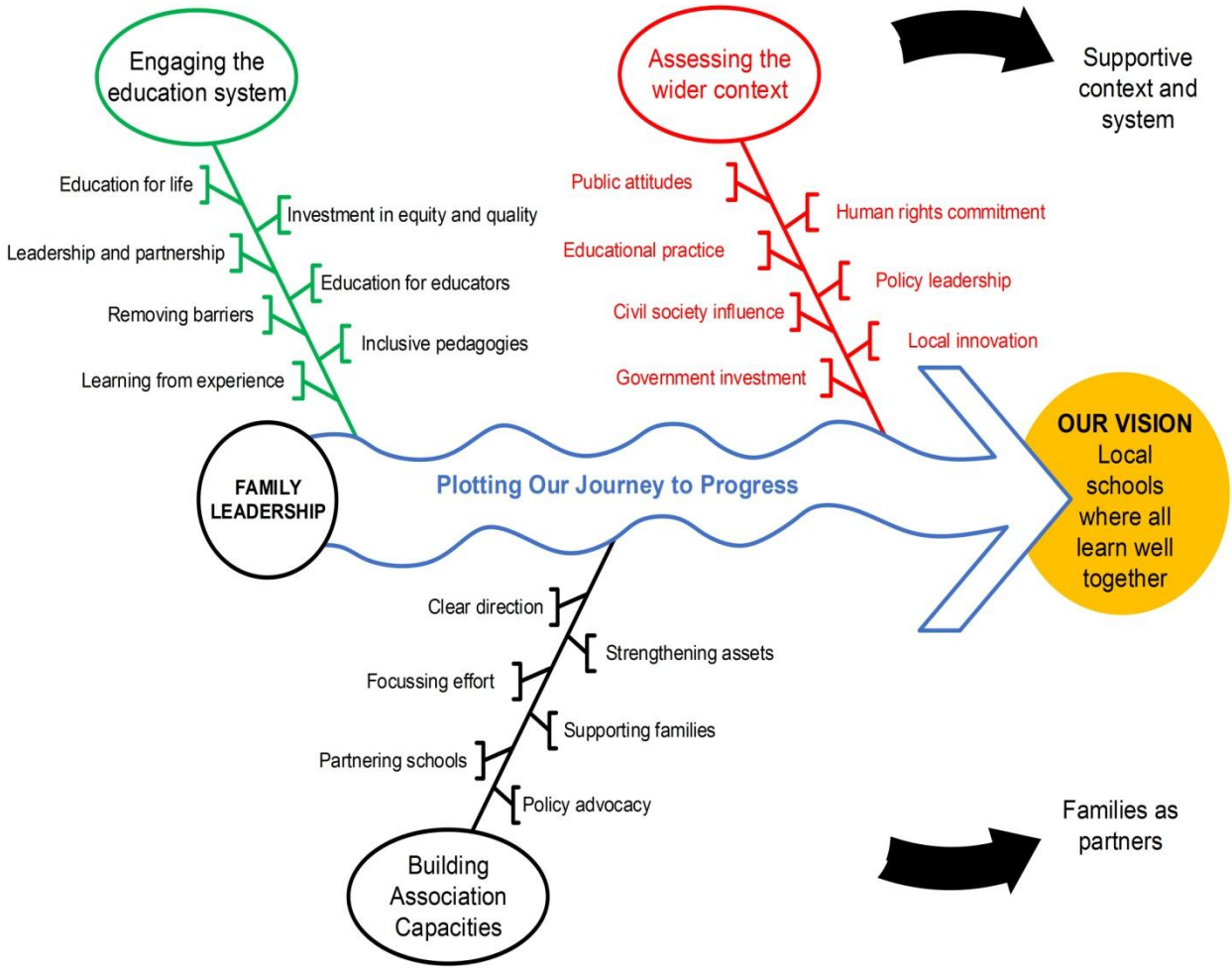
- The extent to which there is policy commitment to inclusive education based on a good understanding that this requires a transformation in educational policies, culture and practices if all learners are to benefit?
- How far there is coherent national leadership for reform?
- Whether international development agencies are supporting reform?
- The current situation in education, including whether there is flexibility in teaching and student assessment, a separate special education system and/or an autonomous private education sector?
- The nature of public attitudes to disability (e.g. shaped by a history of segregation) and professional attitudes (e.g. reliance on medical diagnostic understanding of learner difficulties)?
- The extent to which educational policy is decentralised and offers local opportunities for innovation;
- The strength of family and other civil society (especially disabled people's) associations as advocates and change-makers.

5. Plotting the journey to progress

The fifth tool (represented in the diagram below) brings together the four earlier tools as a guide to association planning. Every family association, whether working locally, nationally or both needs to plot.... and re-plot their chosen pathways to a better future for all learners. *Our three stories illustrate what this has meant, so far, for us.*

As we have seen, association strategy needs to be:

- ✓ built on a clear vision of inclusive education;
- ✓ shaped by an understanding of key elements in the system of education required to support this vision and an appreciation of which of these elements are most in need of attention;
- ✓ grounded in an appreciation of opportunities and challenges in the wider context for educational change;
- ✓ 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; and
- ✓ continually updated in the light of progress (or otherwise) in the strategy and learning from experience about the validity of these understandings and assessments.



Let us end with a message to family members who are, or who are considering how best to contribute to making education better for your children - and indeed all children. Of course, our efforts must start with our own children. We don't all have the energy or opportunity to get involved in campaigning and organising etc. We will all make our own choices - reflecting on our talents, our networks and the situation for our children and the places where we live.

We have learnt that we can best help our own children if we also see what needs to change so many others benefit. We also know that if many families are working together, that will help all of us. Where we get opportunities for wider leadership and influence, we know that we have to find clear ways of expressing our vision for the future and use our leadership to empower other families to feel empowered and make a positive difference.

We have also learnt that sustaining momentum towards inclusion is a life-long struggle, always faced with 'ups and downs'. We have to stay resilient. Of course our families, our friends and above all, the inspiration we get from our children will keep us going.

Can we achieve real change as family members? We hope our personal stories here will encourage all of us to say, in the footsteps of President Obama, **Yes we can!**

Notes.

1. The Committee on the rights of Persons with Disabilities General Comment No. 4. *Article 24: Right to inclusive Education* United Nations, August 26, 2016.

2. For a fuller analysis of the need to secure transformational change in public education systems, see Gordon L. Porter and David Towell (2017) *Advancing Inclusive Education.* Available at: www.inclusiveeducation.ca

3. Marshall Ganz *Why David Sometimes Wins* Oxford University Press, 2009.

4. Inclusion International offers a global knowledge network for inclusive education through its *Catalyst for Inclusive Education https://www.catalystforeducation.com/*

5. For more information on the Latin America network, see: http://rededucacioninclusiva.org/quienes-somos/

6. For an impressive range of mainly English-language examples, see for example: http://worldofinclusion.com/ This site includes an excellent recent video from Eastlea School in Newham: http://worldofinclusion.com/eastlea

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