

Through a Time of a Cultural Change: The experience of Down Syndrome Ireland

History says don't hope
On this side of the grave.
But then, once in a lifetime
The longed-for tidal wave
Of justice can rise up,
And hope and history rhyme
Is reachable from here.
Believe in miracle
And cures and healing wells.

Introduction



Until the early sixties, the genetic occurrence Down syndrome had not yet been identified and when a boy or girl was born with Trisomy 21, the diagnose was “idiotism” or other derogatory

terms. In most cases the only option for families that did not have resources was to place their children to segregated institutions specially arranged by the states for this purpose.

Even in more recent times, legislation around the rights of adults with Down syndrome would become 'wards of court' under the 1871 Lunacy Act, which limited their right to own property, get married or make any significant decision without court approval. It was only in 2015 that the Assisted Decision Making (Capacity Act) finally replaced the Lunacy Act although the Decision Support Service, which is key to the full enactment is still in operation.

Through all these challenging years, Down Syndrome Ireland (DSI) supported children with Down syndrome and their families to overcome stigma, access education, develop skills for independent living and achieve the most basic human rights so they can own a place in this world. Bearing in mind that the UN CRPD was only ratified by Ireland in 2015 the last EU country to do so, it is important to remember the processes and to understand the context of the struggles, the learnings and the determination of families and their OPDs (Organisations of Persons with Disabilities) to deconstruct social prejudice.

Problem background and context

In Ireland, for many years children had to undergo a psychological assessment at age four, which results in recommendations that aim to inform the decision of which education stream would best suit the child and which support resources would be needed. Invariably almost 100% of children with Down syndrome were placed in segregated special schools.

In principle the option of attending a special school or going through the mainstream Irish system has been to a certain extent, at the discretion of the parents. However, in practice the only school that provided adequate support in the form of special needs assistants was the segregated special school.

This made ableism and stigma continue to be predominant in the community, reinforcing a circle of overprotection and low expectations towards children with Down syndrome which resulted in determining their little chances of social inclusion.

The approach

Inclusive education first

Down Syndrome Ireland (DSI) was created in 1971 to promote the rights of children with down syndrome and their families. In those years, education of children with Down syndrome was 100% confined to special schools run by disability services, and still not guaranteed.

The organization's primary aim from its beginning was to support parents in providing them with the tools to ensure that their child got the best start in life by early intervention therapies. While initially the organization did not advocate for one schooling system over another, it believed that the choice should be readily made available to children with Down syndrome and that students should not be forced into special schools, for example, because of a distorted perception of their potential or other challenges that might be associated with sending them through mainstream education.

In the mid 1980's, DS Ireland supported enrollment of the first 10 children with Down Syndrome into mainstream primary schools, who were assisted by a support teacher provided by the organization. The idea that children with Down syndrome could be educated in their local school with their brothers and sisters was considered groundbreaking at the time, and DSI aimed to demonstrate that this is possible with adequate resources. The support teacher visited two schools a day, so that each of the 10 children were seen once a week. Few years after this model was introduced, eight out of these ten pioneering children and families completed primary education in inclusive schools.

Still, the idea of including children with Down syndrome in the regular system, had also to deal with a degree of hesitancy and opposition of important stakeholders such as the National Council of Special Education, special education teachers as well as other parents and the community.

Nevertheless, the association used the evidence backed by research from this model to engage with the government to explore how the model could be used by education authorities around the country to support inclusion of children with disabilities and to advocate for allocation of sustainable state funding for support teachers in the long run. This is when campaigning and lobbying became critical to gain support from the public and address the social attitudes towards inclusion.

Awareness, information, and communication campaigns became necessary to convince key stakeholders but also to advance a process of cultural change. Social inclusion would not take place without the Irish society deconstructing deep rooted stereotypes and misconceptions.

Addressing the new challenges: from lobbying to expertise, partnerships, and advice

Despite the initial success of the pilot intervention, the need to comprehensively address factors influencing attitudes and practices emerged as important as finding practical solutions for inclusion. DSI and other parents' organizations lobbied for the provision of Special Needs Assistants to meet additional care needs of children with disabilities in mainstream schools. The result was making inclusion more common at least at primary school level.

In addition, DSI pushed towards a multisectoral, multilevel approach involving support for parents and professionals, in parallel to the awareness-raising and lobbying, research and training for service providers and family members. DSI held in-service training at its own for all teachers who wished to avail of it. At the last over 35,000 teachers have availed of this.

The development of inclusive policies and practices in education also increased the need of additional support staff for tasks such as helping with clothing, feeding, general hygiene or travel as an escort on school buses, as required.

Convincing administrators and politicians that children could be supported to attend mainstream schools was a huge challenge. It required creating awareness on equal rights of all the children, lobbying for policy changes to optimize inclusive education, sorting out mechanisms for the provision of reasonable accommodation and support in a sustainable manner and disseminate positive examples of children with Down syndrome included as part of the community was all equally important.

Becoming an expert organization

DSI needed to become an expert organization with capacity to generate evidence, inform policy decision making and technically assist the implementation of inclusive strategies.

In 1991 evidence was presented to the Education Ministry about the scheme for inclusive education, including research showing benefits for the students with Down syndrome as well as general advantages for the rest of the children e.g in terms of life and autonomy skills developments.

Some years after, DSI got involved in collaborative research about how to make support available to teachers, with experts in Down syndrome that branches and access to individual consultations for help or advice as part of a resource Centre for inclusive education. A National Resource Team was formed, initially focused on counselling and early intervention, and quickly expanding into a team of experts in health, early intervention, education, counselling and independent living.

These studies were presented to the Minister for Health and led to the establishment of a specialized clinical nursery based at the Department of Pediatrics in the National Children's Hospital, Tallaght as a collaborative effort partially supported and managed by Down Syndrome Ireland.

Today, DSI collaborates with universities to advance literacy programs for adults with Down syndrome as well as programs for Early Years¹, Further Education, Employment and Advocacy.

The development of know-how and skills to play a technical role made the government authorities to see Down syndrome needs from a different perspective, partner with DSI and gradually agree on taking over inclusive principles e.g paying for the support teachers in mainstream education. And ultimately covering the cost of special needs assistants to support the child in the classroom. This was a big step in terms of inclusion and an important outcome of the strategy: it saw a reasonable accommodation and support mechanism being funded by the state rather than by a charity.

Advancing law

The changing of attitudes amongst authorities, professionals and parents and the new understanding of inclusive education challenges and opportunities has to gradually be translated into a new regulatory framework. Having a proper legal, institutional and support framework that is based on a human rights perspective is key to providing a clear horizon for the education system to continue developing even if parts of such a legal framework remain unimplemented in some areas.

The EPSEN Act (2004) emerged as a result of lobbying with the authorities and indeed provided a new comprehensive framework. It clearly approaches the education of people with special education needs in an inclusive environment together with those children who do not have such needs. The Act outlines duties and responsibilities of school boards and principal teachers regarding the provision of reasonable accommodations and support mechanisms for learners with disabilities. Even still pending implementation in many aspects of this legal tool it is already an instrument of gradual change in the way society agrees to deal with diversity and the need off an education system prepared to respond to the needs of all children.

As there were still inequalities and a certain level of discrimination towards children with Ds, DS Ireland commissioned a report from economic consultants to investigate the cost of education a child in a special school and a child in a main-stream school. To make a long story short – there

¹ See and learn, <https://www.seeandlearn.org/en-us>

was no difference, dispelling the perception that the extra resources put towards the mainstream system was not prohibitive.

Thank you for your attention

Addendum: A Future of Independent Living



Having equitable education horizon leads to the challenge of people with Down syndrome having access to work opportunities. This is particularly important when very much as a result of misconceptions among Irish employers that people with Down syndrome cannot cope with employment or are only able to undertake routine, methodical jobs, they are one of the most under-represented groups in the Irish labor market.

Down Syndrome Ireland has tackled this by conducting campaigns to urge employers not to make assumptions about what a person with Down syndrome can do. It created a national employment program to enable adults with Down syndrome to get work placements as hairdressing assistants in salons around the country. And continued lobbying on the government to further incentivize inclusive employment by introducing meaningful grants for employers, as part of an effort to create awareness on the benefits for the Irish society to facilitate opportunities and skills for independent living.

Positive results and unfinished business/shortcomings

Teachers' training, an important prerequisite for inclusive education is still not sufficient in Ireland. This not only hinders changes in teaching practices but contributes to teachers' skepticism and negative attitudes about inclusive education. This insufficient preparation and willingness of teachers is most likely a negative influence on parents and the community as it delays changes in behaviors and maintain the belief that segregated education was best for children with down syndrome. To this day, DSI has a leading role in providing courses and workshops for teachers about Down syndrome a job that would be now better placed with the education authorities.

Tackling multiple disabilities are also a factor that might hinder positive evolution of attitudes if investment in resources to meet complexities are not done. At the beginning of the first decade of 2000, for instance, a number of court cases enforced the Government of Ireland to provide primary school education for children who had multiple disabilities. The High Court concluded ruling a few resolutions that acknowledged the constitutional right of every person in Ireland to free appropriate primary education based on the needs and not limited by the availability of resources.

Still, there is a different social and cultural environment in the Irish society of today. It is assumed for instance that the vast majority of children with Down syndrome will attend their local mainstream primary school. Resource hours for children with Down syndrome in mainstream education which were a big issue in the biggening gradually grew after much lobbying, campaigning and meetings with the education authorities at national and local level.

Down Syndrome Ireland has a long and active history of lobbying and campaigning for and on behalf of people with Down syndrome and their families.² This work has influenced legislation and policy, promoted an equal rights approach on the education of children with Down syndrome, prepared parents to be confident and informed about their rights as well as proactive against persistent barriers. But overall, it ensured that the voices of children and adults with Down syndrome will be heard as part of the Irish society. Its institutional history intertwines with a process of massive cultural changes that are not completed. But provide a better reflection on the way that society understand and value differences amongst its members.

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² <https://downsyndrome.ie/awareness-lobbying/>