



About Leap

Introduction

Leap is a family-led, non-profit organisation working alongside families who have a disabled son or daughter, and who are seeking to build an inclusive, personally meaningful and enriching life for them.

Leap answers the question of why some people with disabilities enjoy a rich and meaningful life while so many others do not. The full and positive lives we hear or read about have not happened by accident. They have taken careful planning, knowledge, resources, hard work and vigilance. We know that immersion within the valued spaces of family and community is one of the primary pathways to a life of meaning, belonging and possibilities. Therefore, we focus on intentional leadership development of families, and on giving families strategies for change.

Leap assists families to explore what a 'Good Life' would look like for their son or daughter, not just now, but also in the future, creating a vision they can articulate to others and use in decision making.

Our focus is on three things - belonging, relationships and valued roles. Many families credit this approach to better outcomes for their family member, especially when compared to the traditional service system.

Through our workshops and one to one sessions, families gain an understanding that relationships, friendships, lifestyle interests, work opportunities and living arrangements will not happen automatically for their son or daughter. Societally, our culture holds low expectations for the lives of people with disabilities. However, by working intentionally to create and sustain opportunities, children are increasingly likely to enjoy more of the good things in life.

We believe that traditional models of services are no longer sustainable and often do not lead to a 'Good Life' for the people being served. Much of what families express as important in a 'Good Life' are opportunities traditional services do not provide.

Much of our work is about assisting people to get a life, not a service. We focus on identifying:

- what people can do themselves
- what they need support to achieve
- what they can create in partnership with others.

We often ask ourselves and families 'how can we use what we have, to create what we need?' Much of what is good in life is not in the currency of money. Families can lose

years, or even decades, in the struggle to obtain better services and more resources; meanwhile their children's life is here and now. When families shift their focus, they can start creating a good life, an ordinary life for the people they love by using the tools they have, rather than waiting for a service solution that may never eventuate.

When paid services are necessary, families can experience more freedom, greater self-determination and better outcomes when their funding is paid directly to them. This allows them to decide what services to purchase and where and when those services are delivered. This reinforces personal choice and control, individual human rights and allows the freedom to create one's own 'Good Life.'

Our Approach

- At Leap, we begin conversations from a different starting place and ask families: ‘What does a good life look like?’ Rather than ‘What services do you need?’
- We provide a supportive, friendly and welcoming environment for families, so that they can create more inclusive and enriching lives for their sons and daughters with disabilities.
- We create value by connecting families with natural supports – positive networks of people who lift them up and assist them. We do not make a virtue of staying focussed on the problem and instead encourage families to turn their attention in a new direction and seek out positive connections. In this way, individual energies get connected, amplified and multiplied through the building of new and positive associations.
- We create space for learning conversations that draw out what people care about enough to take action on, as distinct from what their opinions are about what others should do for them.
- The focus of our work is about recognising the abundance of skills and capabilities around us, seeing not just the problems but the great strengths in communities and how best to utilise them. Communities and neighbourhoods are abundant with talented people and local resources.
- We work with families, educators and policy makers through a range of programmes:
 - Workshops, training and conferences
 - Intentional Leadership development
 - Building community capacity
 - One to one support
 - Provision of Family Friendly Information
 - Planning and facilitation including convening circles of support
 - Advocacy
 - Research
 - Policy Submissions
 - Global collaborations with organisations that share our values and goals
 - Projects and initiatives to support self-direction

Core Principles

Courage – increased reciprocity and trust, drawing people together around the development of a vision for a good life for their family member with a disability.

Relationship based – enhancing people’s relationships with family and others and supporting people to grow their personal networks.

Valued and treasured roles – getting clear on what roles the person with a disability and their family wish to preserve, acquire and strengthen.

Intergenerational work – working with all members of the extended family or network.

‘Hidden’ resources brought into use – making the invisible visible. Asking what we can do ourselves, what can we do with others and where do we need outside help.

Our Achievements to Date

“When I came away after the Leap weekend I was on fire. I really think it’s the way forward and it has really filled in the gap in my head that was missing.

I think it’s brilliant for all agencies to be involved but I think the real change has to be on the ground through families! Families and their aspirations for their loved ones really changes things especially in extended family, neighbours, community and society.

Always remember you can read books, study it but we are the ones who live and breathe this every day of our lives.”

Parent who attended a workshop

- Leap has developed a specific training series called the Supporting Families Workshop Series which consists of four one day workshops. We have rolled this out through workshops for 300 families and workshops for 300 staff members across the country in eight regions.
- We commissioned Dr Louise Dawson, a Health and Social Care Consultant to carry out an evaluation with 353 families/individuals who had connected with Leap. This provided us with evidence-based feedback that our organisation is having a positive impact and which we are using to further develop our offering to families.
- Rachel Cassen and Claire Murphy, the co-founders of Leap, won a Social Entrepreneurs Ireland Award.
- Leap produced the Good Lives Research: *Self-Directed Lives: Perspectives of People with Disabilities and Families* in association with the Centre for Disability Law and Policy, National University of Ireland, Galway (NUIG).
- We presented ‘Good Lives’ Research with NUIG at the Claiming Full Citizenship Conference in the University of British Columbia, Vancouver.
- We were invited by The School of Education, Trinity College, Dublin to collaborate on an Inclusive Education Conference for families and professionals working in education across early years to post-secondary.

Current Situation at Leap

We know from our recent evaluation that the work we do with families is having a huge impact and producing clear positive outcomes, with families reporting that they feel more hopeful and empowered, achieved greater social inclusion for their family member, and worked more closely within their community and social networks. It has also provided significant insight into the barriers that exist for families and highlighted some major issues within the traditional “support system”. These issues need to be addressed if we want to sustain and improve the lives of families who are striving to keep their children on a valued and typical life trajectory.

Leap is a small organisation and we cannot meet the increasing demand from families around Ireland for our services. To that end, we have set clear strategic goals to grow the organisation over the coming years.

However, we currently operate on an annual budget of €120,000 a year. This funds all our activities, including conferences, training, one-to-one family sessions, retreats and collaboration with international organisations; but only allows us to employ one permanent member of staff.

Earlier this year we were invited by our main funder, the Health Services Executive (HSE), which funds 83% of our annual costs, to apply for a significantly increased annual grant to extend our services. Our plan was well received and gained the full support of the Minister for Disability.

However, due to a widespread funding crisis in the Department of Health, Leap has been informed that 100% of our funding will be withdrawn from December 2019 and our work will move into the remit of the Department of Justice. We appealed this decision at the highest level, but have been unsuccessful in re-securing our funding. This unforeseen event has left Leap in a funding crisis.

It is important to note that there has never been any question regarding the quality of our work, however, as a small organisation who is not afraid to ask awkward questions, we are an ‘easy target’ when Ministries are asked to cut costs.

The government’s continued focus on resourcing traditional human services does not affect only Leap. Many families with a child with a disability do not qualify for

these services, and others do not want the life-limiting and segregated service on offer. Additionally, families are also facing the threat of further funding cuts making it even more critical for us to provide positive alternatives to sustain support to those who need it most.

We are now focusing our energy on engaging with a number of other government departments, partners and foundations to seek alternative funding. We remain committed to leading a movement for change around Ireland and across the world. Our goal is the full inclusion of people with disabilities and their families in line with the UNCRPD, which Ireland ratified in 2018. We have a clear plan for expansion, which we have set out below, but we must ensure that we can stabilise the financial security of the organisation as our first priority, before embarking on this next stage of growth for Leap.

We are actively seeking funders and partners to join us in delivering our next Three-Year Plan.

Strategic Goals for Leap 2020 - 2022

Strategic Goal 1: Empowerment

To develop empowerment of families where there is a child with a disability. To identify key targets for the next three years including all leadership activities and identifying key concepts unique to Leap around 'creating a good life'.

Goal Related Actions: Community Connectors

For many years, Leap has been advocating for the provision of 'soft support' roles for families of children with disabilities. Yet funding continues to go into so-called 'hard support' such as clinical support, psychologists and other therapeutic services, with no social or community support provided to the family.

To meet this need, we plan to recruit and train a team of four **Community Connectors to work with families across Ireland**. We will recruit individuals who understand that facilitating inclusion is an art form; that it requires talent, critical thinking and reflective practice. These community connectors will work with families who want to create an alternative to the traditional 'service provision' programme for their son or daughter.





Strategic Goal 2: Education

To develop education focussing on outputs of literature in soft and hard formats available for a range of audiences; link with further and higher education institutions to develop modules for a range of courses in education, social justice, law etc.

Goal Related Actions: Resources for Families

Offer Live-in Family Leadership retreats catering for families across the whole of Ireland.

Provide Information, Guidance, planning and facilitation to families. Access to these supports are through retreats, workshops, via email, telephone, one-to-one contact, our website and social media.

Develop resource materials with families and for families to include

- Planning for an inclusive life
- Building your vision
- Developing your personal network
- Leveraging community support
- How to utilise individualised funding

One of the requests from people who connect with our organisation is that information from our workshops would be widely available. These resources materials will be trialled with families and then made available online as E-Learning modules.

Resources for Educators

Build a network of links with Further Education institutions and develop resources for social policy, human rights and law courses.

Strategic Goal 3: Social Change

To develop work on Social Change and identify key targets for the next three years. To link to evidence-based practice and in-house research, international collaboration, monitoring and evaluation.

Goal Related Actions: Leadership Development

Drive Social Change through a targeted Leadership Development programme for families of people with disabilities.

Develop a Training of Trainers programme in partnership with the Centre for Disability Law and Policy, NUIG. This program will increase individual, family and community assets through a strength-based approach to family leadership development.

Pilot this programme with international partners to elaborate and demonstrate the methodology for the Training of Trainers initiative.





Strategic Goal 4: Be part of an International Movement for Change

To collaborate with other family – led organisations around the world who share our vision and values to develop a Global Family Leadership Network and to work with International rights-based disability organisations to link local knowledge to global processes for change.

Goal Related Actions: International Network of Family Leadership

Continue to develop a Network of Family-led organisations and Family Leaders and work with rights-based global disability organisations to grow their understanding of the role of families in building inclusive lives for people with disabilities.

Strategic Goal 5: Ongoing Monitoring and Evaluation

To develop a monitoring and evaluation framework for Leap's workplans including funding streams, evidence-based practice, Leap team development and governance and accountability.

Goal Related Actions: Administrative Support to Establish a Framework

Provide Administrative Support to assist the Director in establishing a framework for monitoring and evaluating the programme and building an infrastructure to support Leap's work.



Working in Partnership

As parents, all we ever want for our children is for them to be happy and to belong. To have friends, a good education, work that fulfils them. To have a good life. I have two sons and I am no different from any other parent around the world. This is what I hope for both of them. The fact that one of my sons has a disability does not change this.

In 2009, when my eldest son was fifteen, I got together with a friend who worked in services, to set up Leap. Our goal was to assist families, who were confronted by the maze of services for their child and to equip and empower them to find the best solutions for their families. A network of like-minded families was formed who resolved not to lower our expectations for our children, just because of their disability and who began to imagine better and to dream big dreams.

I set up Leap because of a powerful realisation around this time that I had spent years living my life in a quite embattled way - fighting for services for my son. Services, which when secured, often failed to deliver what they appeared to promise. I realised that my son was fast approaching adulthood, and what he needed more than anything was a life and a future which

offered hope, opportunity and a sense of belonging and I began to focus on what a good life looked like for him - and on practising the art of asking.

As Leap has developed over the last ten years, we have established frameworks to assist families to stay on the inclusive life path. We are building a movement of people across Ireland and in partnership with colleagues internationally, that is championing a new way for families to uphold the rights of their family members with a disability to live a good life.

We know that building inclusive and equitable societies starts with investing in families and communities - not seeking to maintain a costly human service system of segregated programs and facilities. Families are their child's greatest resource and most important advocates. A resilient family, connected to community that has clarity of vision and understanding of their unique strengths and gifts, as well as their child's strengths and gifts will be the most effective lifelong advocate for their child. This is what Leap is working towards.



Testimonial



For the last six years I have worked closely with Rachel Cassen, Director of Leap, on a number of projects, and am constantly impressed by her dedication, energy and capabilities in bringing together people from diverse backgrounds to work towards a common goal.

The Centre for Disability Law and Policy at NUI Galway has a strong relationship with Leap, which began with Leap's involvement in research on the personalisation of supports for people with disabilities in Ireland... I was invited by Leap to form the 'Self-Directed Living Research Group' – bringing together families, self-advocates, disability service providers and brokers with a shared interest in community living. We jointly chaired the group, and sought out funding opportunities ...for a series of workshops and a research report on the experiences of people with disabilities and their families in using individualised

funding to create good lives in the community. The workshops we held around the country for this project led to the publication of a dynamic research report, which documented the important lessons learned by people with disabilities and their families on their journeys towards self-directed living. This research was well-received globally and was cited as an example of good practice during the plenary session of a conference in Vancouver in October 2015.

Since the completion of the report, Leap has gone on to develop the project further with a new group of families and we have continued to collaborate and support Leap's work in the fields of inclusive education and equal citizenship. Rachel is always a pleasure to work with and someone whose vision and integrity I greatly admire.

Professor Eilionóir Flynn, Director
Centre for Disability Law and Policy,
NUIG, 2019



***Communities are all around us, close at hand, awaiting
the community building that will make the invisible
assets within them visible in all their abundance.***

Cormac Russell

