



A CASE STUDY IN POLICY
ENTREPRENEURSHIP
THE CENTRE FOR DISABILITY LAW & POLICY
NATIONAL UNIVERSITY OF IRELAND, GALWAY

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Introduction

Carefully researched studies are essential for advocates to make persuasive arguments to legislators and for policymakers to make informed decisions. Too often, however, academic research is disconnected from the real-world concerns of those who make or wish to influence policy and practice. Academics may focus on obscure research topics with little relevance to day-to-day matters. Or they may produce useful findings but write them in such a way as to be inaccessible to the people who could use them to facilitate change.

The [Centre for Disability Law & Policy](#), based at the National University of Ireland, Galway, is a rare example of a university research centre that is having a positive impact on policy and practice. The centre has influenced domestic, regional and international policy in disability rights. It has done so through its accessible research and its training of advocates and academics in the field. Largely because of its demonstrated impact, its work has attracted a number of funders beyond its initial core support from The Atlantic Philanthropies (Atlantic)—ranging from other philanthropies, governments, the European Union (EU) and the United Nations (UN).

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Few such research centres have had this kind of deep and far-reaching impact.

This case study shows how the centre became such an integral resource to policymakers and practitioners. It highlights the practical steps the centre took to become so useful to so many people and institutions. In addition to capturing the centre's key accomplishments, the case study includes its challenges and lessons learned—both for funders considering an investment in such centres focusing on any area and other university centres seeking to make a bigger impact.

While this case study focuses on how one research centre addressed the rights of people with disabilities, the model it provides could inform investment decisions of similar centres dealing with a number of marginalised populations.

Context

In the 2000s, important policy activity was taking place in the disability rights field in Ireland, the EU and internationally. In 2006, the UN adopted the Convention on the Rights of Persons with Disabilities, which entered into force in 2008. The treaty, drafted by people with disabilities and advocates, marked a paradigm shift. Rather than view people with disabilities as objects in need of welfare or charity, the convention recognises disabled people as subjects with rights, including making decisions for what is best for their lives and contributing as full participants in society.

The convention was the first international legally binding instrument setting minimum standards for a range of civil, political, social, economic and cultural rights for people with disabilities around the world.

As of September 2014, 158 countries had signed the treaty, making it one of the few human rights conventions signed by the majority of UN member countries. Additionally, for the first time, the EU became a party to an international human rights treaty when it ratified the treaty in 2011. This was an unprecedented step for the EU and carried both symbolic and practical importance beyond disability. The ratification set a precedent for the ratification of other UN human rights instruments by the EU.

The obligations on the ratifying countries and the EU include repealing inconsistent laws, enacting fresh legislation and directly consulting people with disabilities when making any changes that will affect their lives.

The UN Convention was the first international legally binding instrument setting minimum standards for a range of civil, political, social, economic and cultural rights for people with disabilities around the world.

The new treaty initiated a process of worldwide reform. However, most of the ratifying countries, as well as the EU, did not have the expertise to know how to make the required changes in their policies. Many countries still had laws in place that reflected the old ways of providing services to people with disabilities. These did not ensure their full participation in the decision-making process or in society.

Mirroring these changes at the international level in Ireland, a number of government initiatives in the 2000s provided opportunities to make significant headway in the country for the rights of people with disabilities. Those initiatives included a National Disability Strategy and the Disability Act. At the same time, and in preparation for ratification of the UN Convention, Ireland had to identify the laws and policies it needed to amend to reflect the new paradigm shift for disabled people.

While the potential for change was huge, the capacity to facilitate change was meagre. Some isolated individuals and centres were conducting useful research on disability policy. However, there were none that worked on disability law and policy and none that produced blueprints for change. It was a huge gap at a time when Ireland, the EU and countries around the world needed help in making sure their laws conformed to the UN Convention.

“Most countries and most courts did not understand how to make this shift from a welfare to a human rights approach to people with disabilities,” said Theresa Degener, a professor of law and disability studies in Germany, and vice chairperson of the UN Committee on the Rights of Persons with Disabilities. “What was desperately needed was a think tank in this area.”

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The Creation of the Centre for Disability Law & Policy

Professor Gerard Quinn, one of the key drafters of the UN Convention, had been working in the disability field since the early 1990s. Quinn formed an informal research unit on disability law and policy at the National University of Ireland, Galway, in 2001 based at the law school. When the drafting of the UN Convention began in 2005, the research unit received funding from Atlantic to work on the treaty.

In the mid-2000s, Atlantic supported the development of a research centre that could help embolden advocates for change and contribute directly to the policy process. In December 2006, Atlantic approved an initial planning grant to take the first steps to create a formalised centre on disability law and policy. In 2008, Atlantic followed with a three-year, €2.8 million grant to establish a Centre for Disability Law & Policy at Galway.

“The UN Convention was just coming through, and it was important to monitor how it was being implemented and bring legal expertise to this area,” said Brian Kearney-Grieve, programme executive for the Reconciliation and Human Rights Programme at The Atlantic Philanthropies. “How do you develop and implement legislation? If we look at what others do on disability, there is a lot in service provision and not a lot of focus on developing legislation or on the impact of existing legislation.”

With the formalisation of the centre, Atlantic staff saw the potential to fund something that could have a lasting impact on the lives of disabled people. Atlantic also wanted to help create an infrastructure that would be sustainable and include succession planning.

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Brian Kearney-Grieve, programme executive, The Atlantic Philanthropies

Atlantic's funding allowed Quinn to devote most of his time to developing the centre and implementing its five-year strategic plan. Four full-time staff: a business manager, two researchers and a lecturer, as well as a part-time administrator, provided support.

With the core funding, the Centre for Disability Law & Policy became one of the only centres in the world dedicated to disability law and policy. In 2012, Atlantic provided another €1.5 million in funding for three years.

What Makes the Centre Unique

Instead of producing research that stands alone, the centre starts from an understanding of the opportunities for change in the policy process and tailors its products to influence policy.

Key features include:

- **Staying attuned to the real issues affecting the disability community.** The centre's operating philosophy is "scholarship in action." This means undertaking research that addresses the problems that ordinary citizens face and providing practical policy solutions. A central aim is to give power back to people with disabilities so that they can have control over their lives. Many key players have first-hand experience with disabilities.

"Irish universities have generally been very remote from the community," said Quinn, director, Centre for Disability Law & Policy, School of Law, National University of Ireland, Galway. "This centre was deliberately situated halfway between the knowledge world of the university and the policy world. It was to be attuned to real problems and priorities. It was to be a projection of the university as a good citizen into civic space."

Specifically, the centre's work is to conduct high-quality research on a range of disability policy challenges of critical importance to people with disabilities. It also focuses on providing research that will not only point out problems in policy but offer solutions. The centre's "compass for change" is the UN Convention on the Rights of Persons with Disabilities.

Another key feature of the centre is that people with disabilities have input into the research it conducts. For example, the centre established Local Consultation Groups comprised of people with disabilities, their families or carers and professionals in the field so that it would understand the most pressing concerns disabled people have. Another benefit of these groups is that they can increase the buy-in for the centre's work among participants' membership organisations and serve as dissemination channels.



A central aim of the centre is to give voice and choice back to people with disabilities.

- **Equipping disability advocates with the knowledge to advocate for themselves.**

A crucial tenet of the centre is that people with disabilities are the experts on their lives. The centre's role is to help them develop the knowledge to advocate for themselves, in part by making use of research that they might not have had access to in the past.

One of the centre's areas of work has been to help people with intellectual disabilities establish their own organisation and advocate for what they want—work that took an enormous amount of time but is seen as among its most important accomplishments, according to advocates and the centre staff.

“Self-advocates are usually funded by disability or parents’ organisations,” said Eilionoir Flynn, deputy director of the centre. “The group we are working with wanted a place to meet by themselves, to get up and running and people to consult with when they want to get their views heard. We are very much in the background. We help them figure out what they want to do.”

- **Developing and delivering relevant quality education programmes.** The educational philosophy of the centre is to equip and inspire the next generation of disability policy entrepreneurs in Ireland and in the world.

“We don't want to produce mass amounts of information that barely anyone reads,” Quinn said. “We want to form the next generation of disability policy entrepreneurs—people who are knowledgeable but, more importantly, people who can contribute to the process of change.”

The centre established a number of educational avenues, including an international summer school and master's and doctoral programmes to equip advocates and professionals with the knowledge they need. Inspired by this spirit, the students of the centre started Ireland's first university-based Disability Law Clinic where they provide advice on a range of disability-related legal matters. This clinic is among only a handful of its kind in the world.

- **Producing research that is useful for policymakers.** The centre's research agenda takes the UN Convention on the Rights of Persons with Disabilities as its core focus since it is a key driver of change around the world. Its research focuses on how to translate the generalities of the convention into practical law reform. When new legislation is under debate in Ireland, the EU or the UN, the centre produces research aimed at providing useful information that can help frame the debate and influence outcomes.

Unlike many researchers, the centre staff see one of their jobs as working closely with policymakers when they are developing disability policy. The centre prepares submissions that respond to proposed legislation, produces reports on areas of disability law and writes policy briefs aimed at reaching a wider audience. Centre staff make regular use of social media with an active Facebook page, Twitter feed and [YouTube](#) channel.

“In order to democratise knowledge and fresh insights we harness new media to reach as wide an audience as possible,” Quinn said. “Nearly everything we do—every event we hold—we stream online and archive on our own YouTube site. This has impact as far away as Georgia, Russia, Peru, China, India and Viet Nam.”

- **Collaborating with other research centres.** In order to optimise its impact, the centre works with a broad range of collaborators.

“We see ourselves as a ‘collaboratory’—a space where new ideas can emerge and where new alliances can be forged,” Quinn said. “That means that the centre works very closely with a web of similar research sites across the world.”

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Gerard Quinn, director, Centre for Disability Law & Policy



Centre director Gerard Quinn (left) joins judges from the High Court of India at the inaugural Indo-Irish Legal Capacity Encounter supported by Open Society Foundations.

Accomplishments

Serving as the go-to place for policymakers working on disability rights

The centre can point to a number of accomplishments in Ireland, the EU and internationally. Among the most significant may be informing policymakers and advocates on the provisions of the UN Convention on the Rights of Persons with Disabilities. While the convention marked a massive change in how those with disabilities should be treated, few people outside its drafters and committed activists truly understood its import and how it could be used in policy and practice, said Donal Toolan, a disability rights activist.

“The centre has really helped in developing an enhanced understanding or engagement of the convention as a framework, which would guide how legislation or laws would evolve,” Toolan said. “That sounds like a simple statement but it’s enormous in terms of the different players that have taken advantage of it.”

As one example, the centre published *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities*.

“Without the centre we wouldn’t have gone as far as we are in research,” Degener said. “The most important publications in the field have been produced by the centre in the last five years. *From Rhetoric to Action* is looked to by many people in the government as the guidebook for how to make an action plan to implement the UN Convention.”

The centre has played a central role in supporting a UN working group in drafting a “general comment” for the UN Committee on the Rights of Persons with Disabilities. The general comment provided for the first time a description of the rights and duties of states to provide equal recognition before the law to people with disabilities. The UN will use the comment as the basis for examining signatory countries’ compliance with a key article of the convention.

Changing the thinking about people with disabilities and their rights

In Ireland, the most far-reaching policy changes for people with disabilities were likely to come from the implementation of its National Disability Strategy and reform of policy and legislation that was hindering the country’s ratification of the UN Convention.

In both instances, the centre played a key role in moving policy.

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In 2004, Ireland adopted a new National Disability Strategy, one of the first of its kind in the world. As is often the case with such strategies, strong implementation would be the key to ensuring that the rights and reforms envisioned translated into better, more independent lives for people with disabilities. From its beginnings, the centre produced research and organised events that emphasised the need for policy and legislative reform. Among its work was the publication of *Advancing Ireland's National Disability Strategy: Building on Comparative and International Innovation* with a companion international conference in 2010.

Re-Framing How National Action Plans Should be Formulated

The report included 10 critical success factors to make a national disability strategy work. Its practical recommendations and the conference helped raise awareness about issues relating to Ireland's National Disability Strategy. One recommendation was that Ireland have an implementation plan for its disability strategy.

An implementation plan was subsequently put in place by the government. The minister in charge of the implementation also added more people with disabilities to the monitoring structure of the plan—another suggestion in the centre's report.

Giving Power Back to People—Re-Framing Legal Capacity Law

An additional key piece of the centre's work was removing legislative obstacles for Ireland to ratify the UN Convention. While it was a signatory, in order for Ireland to ratify the treaty it had to first change legislation so it was in line with the human rights framework of the convention. The most critical legislation was a reform of a law on legal capacity. The new law would replace an antiquated one in which people with cognitive disabilities (intellectual, psycho-social and neurological disabilities as well as some forms of dementia) had limited rights in making decisions for themselves.

To influence the new legislation, the centre worked with 15 nongovernmental organisations (NGOs) representing the mental health, disability and ageing fields that had sometimes opposing interests on legal capacity issues. Working with other NGOs, the centre generated proposals, circulated them to members of the civil society coalition, got feedback and signoff and then submitted them to the government. Centre staff also held meetings with officials and carried out press and public awareness, building around the new assisted decision-making capacity bill. The centre's submission pointed out the reforms that were necessary to ensure that the bill complied with the UN Convention.

“The centre's influence on the legal capacity bill has been pivotal.”

“It is the centre that massively changed the focus of the law to see people with disabilities as autonomous.”

Carol Baxter, principal, civil law division, Department of Justice



The centre's events are often held in partnership with government or international bodies and emphasise the need for policy and legislative reform. The proceedings are shared via its website and networks.

“The centre’s influence on the bill has been pivotal,” said Carol Baxter, principal, civil law division, Department of Justice, who oversees the team that is drafting the legislation. “We began the process of improving things for people with disabilities but we were still thinking of them very much with a paternalistic type of approach. It is the centre that massively changed the focus of the law to see people with disabilities as autonomous, and if they need help, the help needs to be given in the nature of support that responds to their autonomy.”

“They set a blueprint that has radically changed the thinking that we are now trying to implement,” Baxter added. “It is a fundamentally different model and in my experience the centre has been at the forefront of the work to change the model.”

The new bill recognises that everyone has the capacity to make decisions. With the right support, people with a cognitive disability would be able to make decisions on important aspects of their lives such as managing money, seeking medical treatment and living with others.

The bill is still going through the legislative process, but because of the centre’s knowledge of the UN treaty, the final version will likely reflect its perspective, said David Stanton, chair of the Oireachtas (the Irish parliament) Committee on Justice, Defence and Equality.

“We worked with the centre and issued a report that was so strong that the Department of Justice completely reversed their approach of what they were doing,” Stanton said. “The legislature has been sold on this because the centre’s approach was so professional. They bring the practice and the academic together.”

It is expected that the much-improved bill will be enacted in 2015, making Ireland one of the first countries in the world to have supported decision-making legislation.



David Stanton, chair of the Oireachtas (the Irish parliament) Committee on Justice, Defence and Equality, travelled to India with the centre to bring and share lessons on legal capacity reform.

Turning European Funding Away from Institutions to Community Living

In 2011, the European Union ratified the UN Convention on the Rights of Persons with Disabilities. It is the first comprehensive human rights convention to which the EU has become a party. As a state party, the EU has the same legal obligations as its member states to make sure that its policies and regulations are in line with the convention. In addition, because the EU is such a large funder to its member states its policies have a massive effect—for good or ill—on the lives of people with disabilities.

Because the policy and funding of the EU has such a profound influence on disability policy in its member countries, the centre staff also spent much of their research efforts working with civil servants and members of the European Parliament in Brussels.

“When the EU signed the convention, everything changed,” said Carmen Arroyo de Sande, former coordinator of the [European Consortium of Foundations on Human Rights and Disability](#). “Before there was no need to think about EU law and policy on disability. Everything had been the responsibility of the states.”

The centre's work helped address a huge problem with EU funding for people with disabilities. The EU's structural funds are one of the biggest financing programmes in the EU. Through those structural funds, the EU had been financing the building of institutions for people with disabilities, even though such an approach had been known for decades to cause harm. The existing regulations, however, were technically complex. Arroyo de Sande and others brought in centre staff to provide the legal rationale for changing the regulations to conform to the UN Convention and to finance community-based care.

"One of the terrible things that happened in the first decade of the EU was that a huge amount of funds were used to build or prop up residential institutions," said Georgette Mulheir, CEO of Lumos, which works to end the institutionalisation of children. "There is evidence that goes back 70 years that shows the harm that institutionalisation causes."

Mulheir said that Lumos could provide European Commission civil servants and legislators with story after story of how EU money was being misspent and the negative impact on children. They could not, however, answer the next question that the EU posed.

"The EU said, 'do you have evidence that misspending the money on institutions is technically illegal?'" Mulheir said. "And we couldn't answer that question. But Gerard Quinn could show that it was contravening the UN Convention. The minute we had evidence from the centre we had a much stronger argument."

In 2012, the centre staff prepared a landmark report for the UN Office of the High Commissioner highlighting the negative impact of EU structural funds in funding new institutions, analysing why this was contrary to its obligations under the UN disability treaty and supporting calls for wholesale change. This academic paper was the foundation for a campaign to make a change in the underlying regulations. The result was a dramatic and historic change of emphasis in the new structural funds. No new monies will be spent on institutions or even the refurbishment of institutions. Instead, the focus will be on assisting states to move away from institutions and to strengthen community-based supports.

Serving as a Trusted Source of Analysis

An indication of the centre's standing as an objective and trustworthy source came when the European Commission asked it for assistance in drafting the EU's first report to the UN on its record in the disability field, which was published in 2014. That report and its research became the basis for the EU's later report on its progress implementing the treaty that it must submit to the UN.



The centre was commissioned by the UN Office of the High Commissioner for Human Rights to write this report on the (mis)use of EU Structural Funds.

The centre's work led to a dramatic and historic change for the EU structural funds from spending money on institutions for people with disabilities to focusing on community-based services.

In addition, a major gap at the European level—which inhibited rational policy making—has been the absence of an authoritative source of legal and policy research and information. The centre realised that unless this gap was plugged then change would remain piecemeal. Therefore, it has collaborated with Maastricht University on the annual *European Yearbook of Disability Law*, the fifth edition of which was published in December 2014.

The report reviews the significant developments at the European level regarding disability law and policy and provides an analysis of pressing challenges in the field. In this way, it provides the ongoing scaffolding needed in a prolonged process of change.

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Producing the next generation of disability policy entrepreneurs

A theory of change also animates the centre's approach to education. As a university-based research centre, much of its focus has been on educating a new generation of "policy entrepreneurs" through its educational programmes. The idea is not only to equip individuals to produce quality research and to advocate on behalf of the disability community but also to make themselves useful by exploiting openings for change and by creating them when they are not in existence. The ultimate hope is that these newly trained individuals will help fundamentally change how society sees disabled people and how disabled people participate in society.

In addition to offering a master's and doctoral programme, the centre hosts an international summer school on disability law and policy, an internship and a fellowship programme.

Participating students are now working in Ireland and around the world influencing policy and practice.



The class of 2013 met policymakers in the European Parliament and other agencies in Brussels. All students of the centre are equipped to become policy entrepreneurs.

Attracting Practitioners, Lawyers and Advocates to the International Master's Programme

The one-year master's programme, launched in 2011, attracts students from around the world. The programme is among the first of its kind. Bolstered by scholarships from the Open Society Foundations, the programme attracts lawyers, practitioners and human rights advocates from around the globe who are seeking to increase their knowledge of disability law.

One such graduate, Elizabeth Kamundia, noted that prior to joining the master's programme, she was working as a disability rights officer at the Kenya National Commission on Human Rights (KNCHR).

"I was aware that while I was doing my best on the job, I was not as well grounded in disability rights as I would have liked to really make a difference," Kamundia said. "For example, KNCHR was charged with monitoring the rights of people with disabilities in Kenya. While preparing to carry out the monitoring exercises, I realised that for some rights I knew what to look out for, like education, but for others, such as legal capacity and living independently in the community, it was really difficult to conceptualise what those rights would entail."

When she returned to Kenya, Kamundia prepared a report for the human rights commission on legal capacity, which includes recommendations for legislative reform that would give people with disabilities more autonomy in making decisions.

"It was at the centre that I first got to understand in depth human rights as they apply to persons with disabilities," she continued. "There was an emphasis on practical application of knowledge. We were also always prompted to consider how the theory we were learning could be made more practical in our countries of origin."

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Elizabeth Kamundia, disability rights officer, Kenya National Commission on Human Rights



Centre alumnae Elizabeth Kamundia (left) and Charlotte May-Simera on graduation day.

To date, 32 students have graduated from the master's programme. Participants in the programme typically go back to work at nongovernmental organisations, government positions, international organisations or practicing as lawyers in their own countries.

Emphasising Practical Change in the International Doctoral Programme

The PhD programme in international and comparative disability law and policy has a similar practical focus. Like the other work of the centre, it starts from a framework of understanding and implementing the rights outlined in the UN Convention. Many of the students are not typical doctoral students. Prior to enrolling, they worked either in the field as service providers or advocates.

Mary Keogh is one such example. She had worked in advocacy in Ireland for more than 10 years on disability rights and knowledge.

“My PhD has enhanced my work and helped me think differently,” said Keogh, technical officer, CBM Australia and international coordinator for the International Disability Rights Monitor—an international network that has been monitoring and reporting on the human rights of people with disabilities. “As advocates, we fall into the trap of demanding change but not necessarily having solutions. Now I can come forward with solutions. Those solutions have been tested and are backed by evidence and research.”

Some seven PhD students have already graduated, having completed studies on a range of topics, such as theories of justice and disability, assisted decision-making, blueprints for people with intellectual disabilities, blueprints for inclusive development and aid in the global south. Another 16 are completing their studies.

Establishing International Summer School that Attracts Students from Around the World

Most people cannot commit to a doctoral or even a one-year master’s programme in their busy lives. To address the needs of those who want to increase their knowledge of disability law and policy, particularly as it relates to the UN Convention, the centre began a one-week summer school, which has attracted some 500 participants from more than 20 countries. Participants include people with disabilities, civil servants, politicians, international human rights lawyers and others. All of the materials are on open source (anyone can log in and watch the programme), which expands the summer school’s reach further.

Centre staff describe it as a crash course for people who cannot take a year off for a master’s programme. The school is designed to equip participants with the insights and skills necessary to translate the generalities of the UN Convention into tangible reform for people with disabilities. Faculty and students also have the opportunity to network and collaborate on projects.

The faculty includes senior academics, practitioners and policymakers from around the world; most have been directly and actively engaged in drafting and implementing the UN Convention. Many presenters are people with disabilities who may not have an academic degree but have other knowledge to offer.

“With the UN Convention, there is an impetus for change. But that change can only occur if there is knowledge about the convention,” said Rosemary Kayess, a human rights lawyer and senior research fellow, Social Policy Research Centre at the University of New South Wales in Australia, who has attended the summer school. “The more we provide opportunities for people with disabilities to engage with education, the more it strengthens their ability to advocate for the rights of people with disabilities.”

Another important aspect of the summer school is to nurture a sense of camaraderie and collaboration, which is especially needed in this still nascent field.

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The Attorney General of Ireland Máire Whelan, SC, presents a summer school certificate to director Gerard Quinn.

“Sometimes when you struggle in your own little space you believe the barriers you are facing are unique to you and become much larger,” said Amita Dhanda, professor of law and head of disability studies at Nalsar University of Law, Hyderabad, India. “When you come to this space you see that you are not the only person struggling. And you see other strategies that can help in your work. It helps with the sense of loneliness you sometimes have.”

Collaborating Actively with Other International Research Centres

The centre has built relationships with other centres of excellence throughout the world, including Harvard Law School, Maastricht University, Leeds University, the University of New South Wales, McMaster University and many others. It collaborates with programmes in disability studies and public policy analysis.

Various projects help to cement these relationships, including the DREAM (Disability Rights Expanding Accessible Markets) network that the centre founded and coordinates. This €3.7 million project is a consortium of five European universities funded by the EU Marie Curie Programme. It attracted 14 PhDs spread among five universities. DREAM brings the centre’s research partners closely together to pursue a common objective. The centre collaborates with others to draft funding proposals, to create new networks and to share insights and knowledge.



The closing conference of the EU Marie Curie DREAM project, led by the centre, brought together principal investigators, researchers and PhD students from five partner universities.

Fostering the Voices of People with Disabilities

A key commitment of the centre is to work closely with civil society groups in Ireland and in Europe to aid their advocacy efforts. Part of that work means enhancing the voices of persons with disabilities through the development of self-advocacy.

One of the centre’s most challenging—and rewarding—pieces of work has been assisting a group of people with intellectual disabilities to form their own organisation. Called the National Platform for Self-Advocates, the group spent two years getting their own organisation established with the centre’s help. It is an independent organisation, which sets it apart from other similar groups. It represents Ireland’s first concerted effort to establish a national platform where advocates with intellectual disabilities can freely express their views and work independently to achieve their goals.



Charlotte McClain-Nhlapo (right), coordinator and disability adviser to the world, Office for Disability and Inclusive Development, USAID gives a seminar at the centre.

Centre staff provided administrative support and helped group members figure out what they wanted to do, but mostly stayed in the background, Eilionoir Flynn, deputy director of the centre, said. The group hired its own facilitator, elected its own board and held its first conference in May 2014, which attracted more than 100 people. Since its inception, the group has written to Kathleen Lynch, Minister of State for Primary Care, Mental Health and Disability, about budget cuts and met with Senator Katherine Zappone to discuss its work.

“The centre helped give us a sense of achievement,” said Joe McGrath, former chair of the National Platform for Self-Advocates. “We knew we could turn to them for the technical support we needed and they kept us up to date with current legislation about the disability sector. I think it might have been difficult for us if we didn’t have the support of the centre.”

The work with people with intellectual disabilities was just one example of the centre’s collaboration with advocates, which sets it apart from most research centres. As a result of this work, many individual advocates are starting to challenge the organisations that have represented them for decades.

The centre is infusing a new sense of purpose and independence among disability advocates.

“People with disabilities come from a culture of passive dependence,” said Martin Naughton, support officer, Disability Federation of Ireland. “The likes of Gerard and the centre gives you the confidence to roll back and say ‘I want a slice of this cake, please.’ We are now less keen to listen to our member organisations with their propaganda. We are inclined to ask, ‘How do your members feel? Do you have evidence for that? Have you consulted with your members?’ Ten or 12 years ago, I don’t know if we would have had the guts to say that to our organisations. They were powerful. It’s different today. In that way, the summer school has helped greatly.”

Naughton said that as a campaigner he is “good at throwing large rocks.” But he said through his work with the centre, he is backing up his arguments in front of parliament and civil servants with facts, many of which he gleaned from research conducted by the centre.

Advancing Positive Visions in Other Countries

At the European level, the centre is collaborating on the PERSON project ([Partnership to Ensure Reform of Supports of Other Nations](#)), which is aimed at capacity building for disabled persons’ organisations in Eastern Europe in order to implement law reform for legal capacity and guardianship.

Through the project, six civil society organisations in the Balkans receive training to gain competence in undertaking the process of legal reform. These organisations then initiate proposals for laws for reform or undertake strategic litigation. Many of these countries have outdated laws and similar problems, including large numbers of institutionalised people with disabilities. As a first step, each partner organisation prepared a report on legal capacity law and policy in its own country. The reports are available for Kosovo, Serbia, Turkey, Bosnia-Herzegovina and Croatia.

Providing Free Legal Information through a Disability Law Clinic

Students participating in the centre’s master’s programme are strongly encouraged to volunteer at the Disability Law Clinic, which, in partnership with the [Free Legal Advice Centre](#), offers free and confidential information on legal issues related to disability on a drop-in basis. To prepare students for volunteering, the centre provides an intensive four-week training on Irish law and disability. Participating students refer people seeking assistance to practitioners, prepare an amicus brief or provide information on how to address legal issues facing those with disabilities.

Since the clinic was launched in 2011, volunteers have worked with a steady stream of clients on a number of issues, including employment, social welfare and housing rights. The National Advocacy Service for People with Disabilities has turned to the clinic for legal information in advocating for their clients. The organisation provides an independent, confidential and free advocacy service.

In the Disability Law Clinic, students provide free and confidential legal information on issues related to disability on a drop-in basis.

Challenges

While the Centre for Disability Law & Policy has become influential in the field of disability policy and practice, it faces some challenges as well. Among the key challenges are:

- **Maintaining its focus on generating useful research and creating new policy entrepreneurs with the loss of core funding.** The Atlantic Philanthropies' core funding ended in late 2014 as a result of Atlantic's planned closure. With the loss of that funding, it will be challenging for the centre to continue its focus on producing research needed by the disability field rather than doing work that is fundable.
- **Avoiding burnout among the staff.** The centre is a small institution with a core team of three to four staff members producing research, working with advocates and overseeing its educational programmes. These individuals are called upon more and more for consultation around the world as governments are beginning to recognise the need to address the rights of people who are disabled and whose population is estimated at one billion. Responding to so many consultations puts the staff at risk of burnout.
- **Ensuring that a sufficient succession plan is in place.** Much of the centre's work has been built around the highly capable leadership of Gerard Quinn. He has built a team around him, including Eilionoir Flynn, deputy director, but a danger still exists that when he retires, the centre will struggle to maintain its high profile in the disability field.
- **Managing its role with the government.** The centre both provides research and briefings to help the government in its policy on disability issues and challenges the government at times. It can be a tricky role to play, Quinn observed.

"It can be hard for the government to see the centre as a resource when we are challenging it at the same time," Quinn said.

- **Focusing enough of its time on working with advocates and advocacy.** While working with advocates and advocacy itself is not the centre's main responsibility, some observers say that the staff could spend more time training disability activists and serving as a credible voice for the disability community. Some advocates also said that the centre could take a more public role on disability issues, such as writing opinion pieces for influential newspapers and going on radio and television news shows.

"I'd like to see the centre more vocal and engaged in a greater public discourse," said Donal Toolan, a long-time disability activist. "The centre could write op-eds and bring the evidence to the public in an accessible way. If you are going to change political attitudes or the legislative mindset you have to demonstrate that there is a significant constituency to support your change. There are people beyond those who are disabled to be brought on board. I want the centre to take some authoritative positions."

Some advocates said that the centre could take a more public role on disability issues, such as writing opinion pieces for influential newspapers and going on radio and television news shows.

Lessons Learned

Lessons learned from the work of the Centre for Disability Law & Policy can be helpful to funders seeking to support similar centres—addressing a number of issues—and to such centres themselves.

Centres

- **Identify openings for change and work backwards.** Instead of crafting an activity to achieve a goal (such as produce a blueprint for legal capacity law reform), the centre identifies realistic policy openings, which may be quite narrow and then works backwards to craft an activity or set of activities meant to exploit that opening, and in time, lead to more policy opportunities.

“You have to always be clear about your theory of change, and everything you do has to be timely and part of a broader strategy,” Quinn said.

This is a different way of working than most academics who often take the position that the cogency of their argument is enough. It is not. Instead, academics can optimise the value of their work in a policy environment by finding small openings where their research is needed by lawmakers and civil servants. As a practical matter, that means paying attention to the policy cycle of government and opportunities to contribute to debates.

To inform their research, the centre has put into place a number of avenues to hear what people with disabilities need.

“By and large government knows what’s wrong,” Quinn said. “Don’t spend the majority of your time explicating the obvious. Put most of your energies into expanding the range of solutions governments have not explored.”

- **Listen to the lived experience.** The staff of the Centre for Disability Law & Policy are there as researchers. They might have experience with people with disabilities, but only those with disabilities know what they need. The centre staff put in place a number of avenues to hear what people with disabilities needed to inform their research, including establishing a Local Consultation Group, setting up a disability law clinic and featuring people with disabilities at their conferences and summer school making presentations and participating in discussions about how laws affect them.

By taking this step, a centre can generate useful research that has actual impact on people’s lives.



The President of Ireland, Michael D. Higgins (left), launching the summer school with Shivuan Quinlivan and Gerard Quinn of the centre.

- **Build alliances, especially among those who might appear to be on the opposite side.** Over time, the centre staff began to work much more collaboratively with a broad range of actors. By working together, the centre and its allies have a much better chance of making an impact. For example, when working on a new assisted decision-making law, the Centre for Disability Law & Policy brought in other interest groups, such as family members of people with dementia, to get their views and ultimate support. The centre consulted with all affected interest groups and made stronger arguments, backed by a cohesive alliance.

Funders

- **Identify a gap, look at why that gap exists and then plan a centre to address that gap.** The gap that Atlantic and the Centre for Disability Law & Policy identified was between theoretical knowledge of the UN Convention on the Rights of Persons with Disabilities and the practical application of that convention by governments. Policymakers were not taking on board the issues of disability rights, and those advocating for the rights of people with disabilities did not understand how the UN Convention could affect policy. The centre helped bridge that gap.



Upon the occasion of her first official engagement, the UN special rapporteur for disability, Ms. Catalina Devandas (bottom right), visited the centre to meet staff and students. Ms. Devandas is now adjunct professor to the centre.

- **Fund the “less sexy” topics.** There are always hot topics to fund, but funders can sometimes make a major impact by supporting important issues to which few foundations are paying attention.

“Disability is the least sexy topic to work on,” said Carmen Arroyo de Sande, former disability thematic coordinator for the European Foundation Centre. “But the centre has put out a model for other people advocating in the social sector. They have put the issue on the map. Funders can make a huge impact when they are willing to support topics that few others are paying attention to.”

Funders can make a real impact by supporting issues that are important but few foundations are paying attention to.

- **Find the right leader and recognise that leader’s strengths and weaknesses.** A centre that is going to make an impact on policy and practice needs a leader who is not only a strong academic but also an advocate. One way to find such a leader, other than just by reputation, is to provide some initial small grants to build a relationship between the leader and the funder. That is how Atlantic began its work with Gerard Quinn and came to fund the centre. It is also important to recognise a leader’s weaknesses and build in supports for those.

For example, Quinn’s strengths are the research he does and his ability to connect with both activists and policymakers. He is not interested, nor does it make best use of his skills, in creating business strategies or work plans, which are also necessary for the success of such a centre. Recognising what the leader of the centre could and could not do, Atlantic provided funding for a business manager whose job—and interest—is to create such plans.

- **Give such centres security and time to achieve impact.** For centres such as these to think and act strategically, funders need to make a multi-annual commitment upfront. Centres need five to 10 years of investment to try and make systemic change around legislation and policy. By including a matching funding requirement or diminishing level of support, funders can build in ways to reduce dependence on their support.

“The best results come from shifting massive systems around. When you are trying to change major systems there is a need for multi-year programmes,” Mulheir said. “The real lesson for funders is to identify a specific problem you want to solve, find and identify the real experts and support them for a number of years. I can’t imagine a major system shift taking less than five years.”

- **Broaden the mission of such a centre’s work.** Many funders stipulate that their grantees can work only in certain countries. But if they broaden their requirements, they can make a deeper impact. When the centre started its summer school, Atlantic could have specified that the school only admit students from Ireland. But Atlantic did not stand in the way of the staff’s desire to bring in participants from around the world. Doing so helped the centre make a global impact and also brought in perspectives that have strengthened its work in Ireland.

Next Steps

The Centre for Disability Law & Policy is taking a number of steps to try and ensure its sustainability and continued impact, particularly with the conclusion of Atlantic’s core support at the end of 2014. Much of its focus is on internationalising its work and influence in research, teaching and civic engagement.

In 2013, the centre appointed Eilionoir Flynn, its long-time senior researcher, as deputy director. The appointment will help provide additional leadership and continuity for the centre. Since its beginning in 2008, the centre has used its €4.3 million in core funding from Atlantic to generate another €8 million in research, projects, and scholarship awards from other sources. Alongside its partners such as the Open Society Foundations, the centre staff plan to apply for other funding, including that arising from Horizon 2020, the largest EU Research and Innovation programme, with nearly €80 billion of funding available over seven years (2014 to 2020).

Plans are well underway for a proposal for the world’s first joint PhD programme on the UN Convention with common core elements. If the proposal is accepted, the centre will lead the programme. This will innovate by bringing together three different disciplines: disability law, disability social science and public policy analysis to keep focused on how to insert ideas in policy and practice to have maximum impact on change. It will link six different European universities and will have a range of formal partners such as the UN Special Rapporteur on the Rights of Persons with Disabilities.

The centre will be part of the new Institute for Lifecourse and Society at the National University of Ireland, Galway, which received initial funding from Atlantic. It joins other research centres at the university—the UNESCO Child and Family Research Centre and the Irish Centre for Social Gerontology. The purpose of the interdisciplinary institute is to produce research informed by citizens’ voices that will make an impact on policies and practices that affect the experiences and well-being of children and young people, people with disabilities and older adults.

The centre has used its €4.3 million in core funding from Atlantic to generate another €8 million from other sources.



The centre is a founding member of the new Institute for Lifecourse and Society which, along with the centre, was core funded by The Atlantic Philanthropies.

Conclusion

In its initial seven years of existence, the Centre for Disability Law & Policy has clearly had an impact in Ireland, the EU and globally. Policymakers regularly turn to the centre for assistance in crafting legislation and regulations that will impact people with disabilities. Centre staff have educated policymakers, practitioners and advocates about the human rights provisions in the UN Convention for Persons with Disabilities and how those provisions must be applied to existing and new laws.

Through its educational programmes, the centre is creating a new generation of “policy entrepreneurs”—people who are steeped in conducting rigorous research that is relevant to the real-world concerns of people with disabilities.

With its citizen engagement work, the centre is giving advocates new energy and confidence to demand change from their representatives.

The Centre for Disability Law & Policy shows what a difference such a centre can make in the social change that many funders seek.



The work and accomplishments of the Centre for Disability Law & Policy are noteworthy not only for their achievements in the disability field but for accomplishing the social changes that many funders seek.

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More information on the Centre for Disability Law & Policy can be found here: <http://www.nuigalway.ie/cdlp/>

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