

# Making a Difference in the Lives of People with Disabilities:

Capturing the Learning from  
Funding on the Island of Ireland



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## INTRODUCTION

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In the Republic of Ireland, people with disabilities and/or mental health difficulties constitute approximately 10% of the population. In Northern Ireland the figure is approximately 20%, influenced in part by the legacy of the conflict. The figures are growing because of increasing population and longevity. In both jurisdictions, people with disabilities face significant barriers to participating in society.

For example, those with disabilities are less likely to be in paid employment, twice as likely to live in consistent poverty and more likely to experience poor health than those with no disability.

Over the last decade, The Atlantic Philanthropies has provided grant funding in both the Republic of Ireland and Northern Ireland to support improved access to justice and services for persons with disabilities. The grantees funded by Atlantic included the following:

### **Republic of Ireland:**

- The Centre for Disability Law & Policy at the National University of Ireland, Galway
- The National Institute for Intellectual Disability at Trinity College, Dublin
- Genio
- The European Foundation Centre
- Irish Mental Health Coalition/  
Mental Health Reform

### **Northern Ireland:**

- Disability Action
- Participation and the Practice of Rights
- The Law Centre for Northern Ireland

## ATLANTIC'S GRANTMAKING STRATEGY

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Atlantic's grantmaking strategy originated in the early 2000s when the foundation recognised the need to move the disability agenda from simply securing legal rights for people with disabilities to also achieving genuine community inclusion and participation.

Atlantic's support evolved in parallel with landmark policy developments that followed, most notably the United Nations (UN) Convention on the Rights of Persons with Disabilities which came into force in 2008. The Convention resulted from decades of work by the United Nations to change attitudes and approaches to people with disabilities.

The UN Convention was the first international legally binding instrument that set minimum standards for a range of civil, political, social, economic and cultural rights for people with disabilities around the world. It was groundbreaking in viewing people with disabilities as ‘subjects’ with rights who are capable of claiming those rights and making decisions for their lives based on their free and informed consent rather than as ‘objects’ in need of charity, medical treatment and social protection.

The UN Convention has been the moral and legal compass for change underpinning much of the work of Atlantic’s grantees in the disability programme. The Convention required signatory countries and the European Union (EU) to adapt their policy frameworks to reflect the new paradigm.

Thus Atlantic’s grantmaking strategy in the disability programme was informed by the need to implement and interpret the new international and national policies at a time of intensive change, whilst also recognising the need to innovate at the service delivery level. Throughout the last decade Atlantic regularly monitored the context across the disability sector and commissioned research regarding specific opportunities for intervention to improve access to justice and services. This led to Atlantic setting the following objectives for its disability grantmaking from 2007 to 2012:

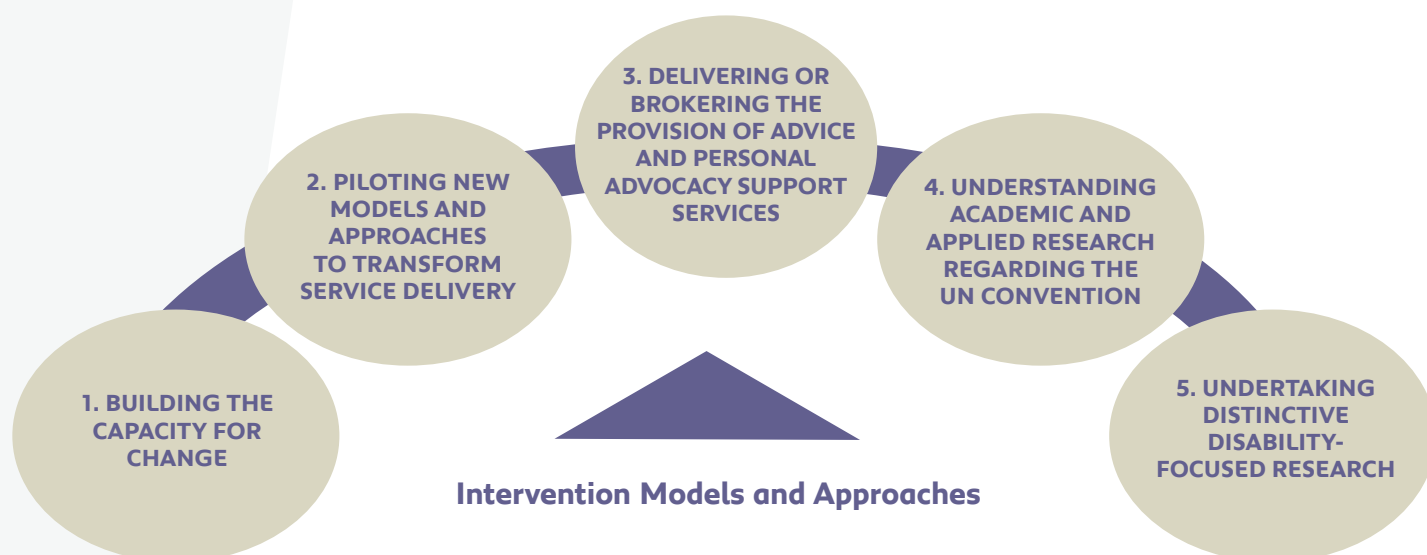
- **Investing in research to inform service provision and advocacy and to monitor the implementation of national disability strategies;**
- **Supporting a cost-effective and person-centred approach to the transformation of services and the way in which they are funded; and**
- **Strengthening strategic and collaborative advocacy including leadership development.**

From 2012 onwards in the Republic of Ireland the key priorities were redefined as firstly building the research and legislative base and secondly demonstrating effective practice leading to policy and service reform. In Northern Ireland the intervention rationale starting in 2012 was more broadly focused on building an enduring capacity to protect and promote rights.

The majority of the grantees received more than one core funding grant from Atlantic to progress their organisational objectives. This paper summarises the achievements of the grantees and the lessons learned based on a programme of research conducted with grantees in 2014.

# INTERVENTION MODELS AND APPROACHES

Atlantic grantees deployed a range of intervention models and approaches to bring about improved access to justice and services for people with disabilities. While in practice the boundaries between these are somewhat blurred it is useful to categorise them as per the diagram:



## Headline Impacts

1. Supporting the implementation of the United Nations Convention on the Rights of Persons with Disabilities
2. Re-orientating European Union Structural Funds towards community-based care
3. Influencing the development of national strategies
4. Securing significant and strategic legislative gains for people with disabilities
5. Improving representation of individuals with disabilities and judicial decision-making
6. Seeding innovative models of person-centred support and service delivery for people with disabilities
7. Applying participative human rights-based models to bring about service improvements for people with disabilities
8. Mainstreaming inclusive third-level college education for individuals with an intellectual disability
9. Building capacity to support legislative change and successful engagement in policy reform
10. Creating a more cohesive disability sector with enhanced political influence to affect future progress

# HEADLINE ACHIEVEMENTS OF THE DISABILITY PROGRAMME

With the support of Atlantic, grantees have been able to deliver substantial impact. Those key impacts include:

## ADVANCING LEGISLATIVE CHANGES AND DEVELOPMENTS

### **Supporting the implementation of the United Nations Convention on the Rights of Persons with Disabilities**

Atlantic grantees advocated and built support for the optimal implementation of the UN Convention. For example, Disability Action was at the heart of a successful campaign to persuade the United Kingdom (UK) government to ratify the UN Convention in 2009 (which was necessary for Northern Ireland as it is a devolved administration within the UK). Disability Action has since become a key and effective watchdog in the implementation of the Convention. Their CEO has been part of a select group of global nongovernmental organisations invited to participate in the UN Conference of States Parties to monitor and advise on the global implementation of the Convention.

The advent of the UN Convention required signatory countries and the European Union to adapt their own policy frameworks to reflect the new paradigm. Atlantic grantees provided assistance to help the European Union and member countries make the needed changes. The Republic of Ireland for instance signed the UN Convention in March 2007 but has yet to ratify it. The primary reason is that it has outdated legislation on legal capacity for decision-making on the part of people with disabilities that is not in compliance with the Convention. The Centre for Disability Law & Policy helped draft new legislation on assisted decision-making<sup>1</sup> to replace an antiquated law in which people with cognitive disabilities had limited rights in making decisions for themselves. The centre was a key part of a working group of civil society organisations that developed proposals on the new bill.

The input from the centre was pivotal in changing the focus of the law to view people with disabilities as autonomous individuals who, with the right support, would be able to make decisions on important aspects of their lives such as managing money, seeking medical treatment and living with others. The new bill is still going through the final legislative process.

In addition, the European Foundation Centre mobilised the foundation sector across the European Union to ensure that European governments and other relevant stakeholders committed to and supported the ratification and implementation of the Convention. For the first time, the EU became party to an international human rights treaty when it ratified the treaty in 2011. This was an unprecedented step for the EU.

<sup>1</sup>Assisted Decision-Making (Capacity) Bill 2013 – (<http://www.oireachtas.ie/viewdoc.asp?fn=/documents/bills28/bills/2013/8313/document1.htm>)





The European Foundation Centre through its Consortium of Foundations on Human Rights and Disability also shaped European debate about the strategic direction and dynamics of European disability law reform and informed the development of the European Disability Strategy 2010-2020 adopted by the European Commission. As a result, there is now an enhanced level of legal protection for people with disabilities across the European Union and better capacity to make sure that the UN Convention is well applied and understood on the ground.

The importance of the global reach and impact of the funded organisations in this regard cannot be overstated given that the UN Convention on the Rights of Persons with Disabilities is the key human rights instrument for people with disabilities.

### **Re-orientating EU Structural Funds towards community-based care**

The EU Structural Funds is the largest financing programme in the European Union. A major criticism of the funds in the past was that they were used to finance projects that failed to optimise the prospects for community living for persons with disabilities. In some instances they were used to maintain or open new institutions instead of transitioning monies and services to the community. This was not helped by the fact that the underlying regulations appeared permissive toward this investment which was not conducive to enabling people with disabilities to live their lives in the community on an equal basis with others.

In 2012/3, with the next phase of the Structural Funds imminent and the regulations due for renewal, the European Foundation Centre and The Centre for Disability Law & Policy made significant contributions to the EU-wide debate on the future role of the Structural Funds as a mechanism to fund community-based care for people with disabilities.

The centre prepared a report that highlighted the negative impact of the EU Structural Funds in funding new institutions, analysing why this was contrary to its obligations under the UN Convention, and supporting calls for wholesale change. The paper was used as the foundation for a campaign to make a change in the underlying regulations. The result was a dramatic and historic change in emphasis in the new Structural Funds. The rights of people with disabilities are better protected, there is provision for the delivery of community-based care for people with disabilities and a task force of human rights funders is mobilising to work on the transition from institutional to community care.



### **Influencing the development of national strategies**

Grantees focused on ensuring that their governments developed strategies that addressed the rights of people with disabilities. For example, the Centre for Disability Law & Policy monitored progress on the implementation of the Republic of Ireland's National Disability Strategy, particularly on advocating for reforms to ensure that it was in compliance with the UN Convention. Genio also significantly influenced Ireland's 'Value for Money and Policy Review of Disability Services' with the resulting report identifying Genio's model of individualised supports as the way forward for future state service provision.

In the mental health arena, meanwhile, Mental Health Reform has held the government in the Republic of Ireland to account for the full implementation of 'A Vision for Change', the national policy framework that provides the basis for reforming mental health services toward the delivery of person-centred and recovery-oriented services. Mental health service users historically had low visibility due to the nature of mental health difficulties and the stigma of mental illness. However, through the advocacy and high profile campaigning efforts of Mental Health Reform, people with mental illness are challenging the status quo and bridging the gap between the espoused government policy and practice.

Indeed in its 2015 Operational Plan, the Health Service Executive's Mental Health Division has now made a clear commitment to address a number of gaps in services that Mental Health Reform members and supporters have highlighted through their campaigning efforts in recent years. These include commitments to strengthen the response offered by Accident and Emergency departments to people in crisis and to extend mental health services to weekends. Both developments will ensure that people are supported more effectively in their local community and will reduce unnecessary and costly hospital stays.

Furthermore, a cornerstone of a recovery-oriented mental health service espoused in 'A Vision for Change' (and advocated by Mental Health Reform) is the involvement of people who use the service and their family members/carers. Again the campaigning efforts of Mental Health Reform have resulted in a commitment to increase service user, family and carer involvement in adult mental health service planning. This, along with the introduction of peer support workers in mental health services, is sending out a powerful message of recovery to those experiencing mental health difficulties.

### **Securing significant and strategic legislative gains for people with disabilities**

Grantees have played a pivotal role in influencing key pieces of legislation to protect and further the rights of persons with a disability and in related lobbying and policy input. For instance in Northern Ireland the Law Centre formalised and led a Mental Health and Learning Disability Alliance comprising government agencies, professional associations and key voluntary sector and user-led organisations in the field. The Law Centre and the Alliance lobbied hard for a single mental health and legal capacity act on the basis that the integration of the two issues ensured a more coherent and effective approach to the development of modern, ethical, rights-based mental capacity law in Northern Ireland.

The Department of Health, Social Services and Public Safety originally resisted this approach. However, following a Law Centre seminar attended by the key policymakers from the department, it changed its approach and agreed to move forward with a single bill. As a result Northern Ireland will be the first UK jurisdiction to implement a single mental health and capacity act, abolishing outdated individual mental health legislation. The outcome will be no longer treating people with mental health difficulties as 'special cases', which has led to discrimination.



The Centre for Disability Law & Policy, meanwhile, has established a reputation as a global centre of expertise on disability law and policy and has become an asset to legislators and policymakers in Ireland, EU and the UN. The centre has been prolific in the production of legislative submissions and expert advice and played an important role in driving changes in the law. A case in point has been the clarification of the supported decision-making model and consequential reform of Ireland's outdated legal capacity legislation.

Ireland is now a world leader in terms of innovative draft legislation on legal capacity. This work has served to strengthen the voice of the centre on an international stage. The centre is active in advising on best practice in capacity law reform to the UK House of Lords Select Committee, across 24 EU member states via the European Union Agency for Fundamental Rights and to the United Nations Committee on the Convention on the Rights of People with Disabilities.

### **Improving representation of individuals with disabilities and judicial decision-making**

Atlantic grantees in both jurisdictions have been active in providing or brokering the provision of advice and personal advocacy support services to people with disabilities through advice lines, clinics and individual casework.

Some of the case work has extended to legal representation and support in cases of strategic importance, which has developed a much greater awareness of the rights of people with disabilities in the courts, judiciary and legal profession. Furthermore the outcome of some of the strategic test cases taken and won are having enduring and far-reaching positive impacts in terms of the rights of people with disabilities.

A case in point is the JR47 case brought by the Law Centre in Northern Ireland on behalf of an adult with a mild learning disability who had waited more than six years to move out of a long stay hospital and into the community. The basis of the judicial review was that at all times during his residence at the hospital he was legally entitled to have his community care needs assessed and reviewed on at least an annual basis.

The ruling from the case has transformed community care duties for people with disabilities in similar situations. The judgement also restored principles of independent living by backing the resettlement of voluntary patients in supported accommodation and emphasising that their care needs must be assessed regularly with care plans in place. It is having positive long term implications for the rights of many people with learning disabilities residing in long stay hospitals who want to live a more independent life.

Prior to Atlantic support, there had been a dearth of cases in relation to the legal rights of people with disabilities. The greater depth and focus in this area has had far reaching and long term implications for the human rights of those with disabilities. It has also helped to make policymakers and care providers more aware of the need to carefully consider the rights of people with disabilities when formulating and implementing policy.

## PROMOTING NEW MODELS OF SERVICE DELIVERY

### Seeding innovative models of person-centred support and service delivery for people with disabilities

Atlantic support has enabled grantees to develop and test new models of person-centred support and service delivery, consistent with espoused government policy.

For instance, Genio has incentivised change to reframe service provision towards a person-centred model while simultaneously building confidence amongst service providers to think differently – in three fields of operation – disability, mental health and dementia. This person-centred approach has been characterised by Genio as Supported Self-Directed Living which refers to the provision of individualised supports that enable people to make their own decisions and direct their own lives (with the assistance of an advocate/family member if necessary).

Between 2010 and 2013 Genio supported 210 projects designed to introduce personalised supports to people with disabilities, mental health difficulties and dementia through innovation grants. This has been enabled through resources and joint work with Atlantic, the Department of Health and the Health Service Executive in the Republic of Ireland. Funding has been used to seed new initiatives to enable personalised community supports to be established while traditional resource intensive models (such as institutions) are wound down. Based on April 2014 quarterly monitoring data, these funded projects had impacted 14,063 lives and were providing 4,458 people with personalised services thus effectively shifting the locus of control from the service provider to the service user. In addition, through these funded projects 8,365 staff and family members had received training and support.

The combination of the innovation funding and training has enabled a major cultural shift amongst participating service organisations from ‘doing things for people’ to ‘supporting people to look after themselves’ and an environment in which positive risk-taking is more legitimised.

Overall the emerging evaluation evidence from funded innovation projects suggests that personalised arrangements are producing better outcomes for service users<sup>2</sup>. These improved outcomes are especially evident in indicators of social inclusion and quality of life and in relation to individual aspirations. In terms of cost comparisons, on the whole personalised options are proving to be less costly than congregated settings or group homes.

In achieving the above degree of reach, Genio has been successful in starting to break down the divisions between different sectors of health and social care - disability, mental health and dementia – by articulating the common support needs across all three. These typically include supports in living independently or remaining at home, supports in accessing work and social/leisure activities and supports in making choices and being self-determined.

<sup>2</sup> <http://www.genio.ie/measuring-impact/disability-mental-health-research/evaluation-of-personalised-supports>

## Applying participative human rights-based models to bring about service improvements for people with disabilities

Participation and the Practice of Rights developed an intervention model that embodied a participative rights-based approach to social justice at the local community level. It was successfully applied in the disability/mental health arena by the Belfast Mental Health Rights Group which secured agreement from the Minister for Health in 2010 to put in place a 'Card Before You Leave' appointments system for mental health patients across Northern Ireland.



The 'Card Before You Leave' scheme ensures that any Accident and Emergency patient with mental health issues who is considered safe enough to go home is given a written appointment for a full psychiatric assessment within 24 hours of leaving hospital. Essentially it ensures that people remain tied into services when they are particularly at risk and is widely acknowledged as a 'lifeline' to those in distress and their families/carers. This work took place against the backdrop of an ever increasing problem of suicide in Northern Ireland. 'Card Before You Leave' has resulted in the number of mental health patients who do not attend their follow up appointments falling by almost half.

The Belfast Mental Health Rights Group continues to gather evidence about problems in mental health services from other service users and carers through surveys, case studies and focus groups and hosting workshops showcasing its campaign. The workshops were attended by mental health groups, community activists and nongovernmental organisations. Feedback indicates a desire among other groups and individuals to use the Participation and the Practice of Rights-based approach to tackle deep rooted problems in mental health services in Northern Ireland. Thus there is a lasting legacy not just in terms of improved service provision but in the development of a toolkit<sup>3</sup> centred on a participative rights-based approach to social justice that can be applied more broadly.

<sup>3</sup> For more information about the approach of Participation and the Practice of Rights, see: <http://www.pprproject.org/about-ppr>



## Mainstreaming inclusive third-level college education for individuals with an intellectual disability

The core mission of the National Institute for Intellectual Disability in Trinity College Dublin is providing access to a mainstream college education for individuals with an intellectual disability. The ultimate goal is for students with intellectual disabilities to be admitted and financed via the central admissions office in the same manner as other third level students.

The concept is both ambitious and ground-breaking in terms of challenging models of learning and promoting the integration of education for individuals with an intellectual disability into the mainstream of Trinity College Dublin which has a prestigious and high-ranking reputation for academic excellence. The National Institute for Intellectual Disability educational offer is a hybrid of a core course for individuals with an intellectual disability – a Certificate in Contemporary Living - combined with the opportunity for students to attend other lectures across different faculties, schools and departments within Trinity College Dublin.

The certificate focuses on academic skills, work related and social skills and the enhancement of independent living skills. Over the course of the two years most students do a work placement, travel abroad and are supported in planning for their futures. There has been a steady demand for the certificate in Contemporary Living since the outset (about 20 students per intake) which validated the Institute's founding vision that there was a gap in the Irish system for provision at third level to cater for the educational needs of people with an intellectual disability and support their transition into adulthood.





The existence of the National Institute for Intellectual Disability and the certificate programme prompted other institutions within the Republic of Ireland to consider an inclusive educational offer for people with an intellectual disability. In all cases the certificate programme was not transferred in its entirety, but other institutions introduced their own variant. The National Institute for Intellectual Disability therefore acted as a catalyst for mainstreaming inclusive education for people with intellectual disability within Ireland.

## **STRENGTHENING THE CAPACITY OF THE SECTOR**

### **Building capacity to support legislative change and successful engagement in policy reform**

The Centre for Disability Law & Policy at the National University of Ireland, Galway acts as the central hub in an international network dedicated to the education of disability policy entrepreneurs through their PhD and master's degree programmes in international and comparative disability law.

The master's programme, which is now in its fourth year of operation, is widely acknowledged as one of the pioneering educational programmes in the world. It has been successful in terms of leveraging support from the Open Society Foundations for funding scholarships and an accessibility support fund. The programme attracts lawyers, practitioners and human rights advocates from around the world who are seeking to enhance their expertise in disability law.

Alumni of the programme continue to make their mark on the international stage in working for the rights of people with disabilities through posts in international nongovernmental organisations, government policy roles or the legal profession (for example, the recently appointed Attorney General of Zambia and the Research Co-ordinator for the UN Special Rapporteur on the Human Rights of Persons with Disabilities).

In addition, an annual summer school hosted by the centre typically attracts more than 100 participants from over 30 different countries from Africa, Asia, Latin America and China and is believed to be the biggest such event in the world. The faculty includes senior academics, activists, practitioners and policymakers from around the world, most of whom have been directly and actively engaged in drafting and implementing the UN Convention and many of whom are people with disabilities.

In Northern Ireland, Disability Action has reached a broad spectrum of people with disabilities and their families, nongovernmental organisations, service providers and policymakers through various accredited vocational education and training programmes. Collectively these programmes enabled the service provider and policy community to appreciate (and articulate) the concerns of people with disabilities and understand the mechanisms and frameworks needed to translate the United Nations Convention on the Rights of Persons with Disabilities into practice.

## Creating a more cohesive disability sector with enhanced political influence to affect future progress

Historically on the island of Ireland the relative weakness of disability organisations and fragmentation in the sector diminished their political influence and hindered progress. The investment from Atlantic has brought a greater degree of cohesion to the disability sector and substantially changed the welfare of people with disabilities as a result. There is now a legacy of highly respected strategists, informed activists and campaigners who have the skills and political influence to affect future progress.

Creative partnerships and collaborative structures have been formed around particular issues such as the Mental Health and Learning Disability Alliance which came together on the successful campaign for the single mental health and capacity act in Northern Ireland. In addition, an alliance of civil society organisations of which the Centre for Disability Law & Policy was a core member, formed around a new law on assisted decision-making in the Republic of Ireland.

Furthermore, the Atlantic investment in equipping disability advocates with the skills to advocate for themselves has created key collaborative structures in both jurisdictions that will continue to have an enduring impact in securing improved access to justice and services for people with disabilities.

Examples of these are the networks of activists formed during Atlantic support. In Northern Ireland, the REAL<sup>4</sup> network is a group of more than 40 disability activists established and supported by Disability Action. In the Republic of Ireland, the National Platform of Self-Advocates provides an independent and neutral space for advocates with intellectual disabilities.

<sup>4</sup> Rights, Empowerment, Action and Lobbying (REAL) Network - <http://www.disabilityaction.org/centre-on-human-rights/outreach/rights-empowerment-action-lobbying-network/>



## KEY LEARNINGS

There are a number of key learning points that can be distilled from the work of Atlantic grantees in the disability field. These are detailed below along with some of the challenges that grantees have encountered in order to inform the work of organisations working in this field around the world and funders that might support them to do so.

### **Innovative policy is not sufficient in itself to drive meaningful change in the lives of people with disabilities**

Neither jurisdiction has lacked the policy ambition to secure better rights and services for people with disabilities. The issue has been the pace of reform and change versus espoused policy intentions.

For example, in the Republic of Ireland the government has committed to an ambitious reform agenda with firm pledges to provide access to individualised personal and social supports and services needed for people with disabilities to live a fully included life in the community. Despite those stated policy intentions by the summer of 2014 the reallocation of resources towards person centred models/ individualised supports had not occurred at scale and had not yet achieved significant momentum.

At that point stakeholders interviewed in the disability arena in the Republic of Ireland stated that only an estimated 3% of the State's disability budget was linked to individualised models and that just an estimated 300 people with disabilities were accessing individualised funding. Those interviewed stated that there were multiple issues underlying these challenges, including institutional inertia, resistance to change, uncertainty arising from austerity and a perceived need to better understand the benefits to be gained from newer models of individualised supports.

Set against this, grantees in Atlantic's disability programmes (for instance Genio) have played an important role in terms of establishing a 'can do' attitude, energising people, building appetite and delivering engagement in demonstration projects to test espoused reform intentions. In effect they have demonstrated the 'art of the possible'. A key learning point from this is the added value of having a 'demonstration and challenge' function independent of government to promote espoused reform and policy imperatives. Specifically the juxtaposition of Genio between the private and public sectors (and the degree of independence it has offered) enabled Genio to gain a perspective on barriers to change and then create pressure within the system to move towards a more person-centric approach consistent with reform intentions. Indeed it is clear that the status of support from Genio backed by the Health Service Executive and the Department of Health, yet independent of both, has been important in providing 'respected space for innovation' to test and demonstrate reform intentions.

Looking ahead there will be further traction in expediting reform intentions. In December 2014, Atlantic made a \$20 million grant to Genio to catalyse the development of a Service Reform Fund with the Health Service Executive to improve the lives of people with disabilities and mental health difficulties in Ireland by embedding and scaling this model of service delivery. The contribution is conditional on the Government investing at least \$47.3 million over three years in the Service Reform Fund.



## Capacity building is vital in building the confidence and culture for change

Capacity building has been instrumental in building the confidence amongst people with disabilities and their families, service providers, policymakers and implementers that new ways of working to secure improved rights and services could be effective alternatives to the status quo.

For instance in the case of the campaign in Northern Ireland for a single mental health and capacity act and the new assisted decision-making bill in the Republic of Ireland, a key focus was building the capacity of civil society organisations and disability advocates to create an informed consensus on the change that was needed. Simply having expert advice on drafting new legislation in the absence of capacity building would not have been effective.

Similarly in the case of Participation and the Practice of Rights a structured toolkit based on a participative human rights approach was instrumental in building the capacity of a vulnerable constituency to fully embrace and effect substantial policy change. Evidence gathering and research alone would not have delivered the same result.

A final example is in relation to Genio where feedback from senior policymakers suggests that their capacity building expertise has had a central role in their success in 'seeding' new person-centred approaches, in building confidence and in anticipating and tackling resistance to change. In effect policymakers said that if it was 'just about giving out innovation grants' to pilot and test new service models, the government could have done that on its own.





## **Dissemination is crucial given the European Union and the global relevance of the work undertaken by the disability grantees**

At the outset of Atlantic support through its disability programmes governments around the world and the legal profession did not know how to make the shift from a deficit and welfare approach to a human rights-based approach with respect to people with disabilities. That need was expedited with the advent of the UN Convention on the Rights of Persons with Disabilities.

The UN Convention created an opportunity for Atlantic grantees in several domains such as policy reform, driving legislative change and in testing new service models. Doing this work connected grantees to a like-minded demand around the world. Indeed several of the grantees, notably the Centre for Disability Law & Policy, the European Foundation Centre and Disability Action have become real assets to legislators and policymakers in the EU and the UN as well as on the island of Ireland.

Effective dissemination and focused network development are central to this. One challenge encountered by grantees is that they are often called upon as experts by Ministers and senior policymakers to advise informally (e.g., on draft wording of legislation/ legislative amendments before they are issued). Consequently the full impact of their work may not be acknowledged and may not be capable of being disseminated.

## **Factoring in sufficient time and resources to effect substantial policy change for people with disabilities may produce a better outcome**

This was evident in the case of the Law Centre-led campaign for a single mental health and capacity act in Northern Ireland. While a law has not yet been enacted, the work was pioneering and will ensure a more coherent and effective approach to providing a framework of rights and safeguards for people with disabilities.

It was also evident in the case of Participation and the Practice of Rights where significant time was required to support vulnerable groups to fully embrace and effect substantial policy change. Challenges can be encountered in sustaining such campaigns, in particular keeping all of the related stakeholders on board when the timelines become protracted. In this context philanthropic sources of funding were noted to be vital alongside volunteer efforts.

Finally, the importance of factoring in a degree of additional involvement and resources in terms of participation of people with disabilities to cater to health issues and demands and changing circumstances was also a key learning point. This was relevant in structures to advocate for change (e.g., the REAL network in the case of Disability Action) and in longitudinal evaluations to provide evidence for the efficacy of new service models (e.g., in the case of Genio).

## CONCLUDING COMMENTS

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Atlantic's grantmaking strategy in its disability programmes has been highly successful in advancing rights for people with disabilities and in achieving genuine community inclusion and participation. Benefits have extended well beyond the island of Ireland with the work of many of the grantees having European Union and global reach and impact. It took place against a backdrop of intensive change in the disability rights field with the UN Convention on the Rights of Persons with Disabilities as the legal and moral compass for reform. The foundations for substantive and meaningful change are now in place and there is a supporting body of evidence to inform future work in transitioning to a human rights/person-centred approach.

Some of the big 'wins' are still in the pipeline such as the single mental health and capacity act in Northern Ireland and the new law on assisted decision-making in the Republic of Ireland which moves it closer to being in a position to ratify the UN Convention. Furthermore despite ambitious policy intentions, the pace of overall government system-wide reform to date has been slow, attributed in part to institutional inertia, resistance to change and uncertainty arising from austerity.

However recent developments in the Republic of Ireland such as The National Implementation Framework, which is a roadmap to take action on the government's Value for Money and Policy Review of the Disability Services Programme, reaffirm the intention to 'fundamentally reform the system from top to bottom'. This framework sets out a number of concrete actions, assigned responsibilities, performance targets and monitoring arrangements needed to make sure that the reform of disability services is achieved in a planned, timely and cost effective manner. This implementation framework will create additional momentum in terms of the pace of reform. The expertise developed through Atlantic support to the disability field will be instrumental in informing this process.

## GRANTEE CONTACT DETAILS

### REPUBLIC OF IRELAND

The Centre for Disability Law & Policy  
at the National University of Ireland,  
Galway

**[www.nuigalway.ie/cdlp/](http://www.nuigalway.ie/cdlp/)**

The National Institute for Intellectual  
Disability at Trinity College Dublin

**[www.tcd.ie/niid/](http://www.tcd.ie/niid/)**

Genio **[www.genio.ie/](http://www.genio.ie/)**

The European Foundation Centre

**[www.efc.be/](http://www.efc.be/)**

Irish Mental Health Coalition/  
Mental Health Reform **[www.](http://www.mentalhealthreform.ie/)**

**[mentalhealthreform.ie/](http://www.mentalhealthreform.ie/)**

### NORTHERN IRELAND

Disability Action

**[www.disabilityaction.org/](http://www.disabilityaction.org/)**

Participation and the Practice of Rights

**[www.pprproject.org/](http://www.pprproject.org/)**

The Law Centre for Northern Ireland

**[www.lawcentreni.org/](http://www.lawcentreni.org/)**

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Trinity College Dublin, Cover photo and page 11

Centre for Law Disability Law and Policy, page 5

Disability Action, page 6

REAL Network, page 13

Genio, page 10 & 15