## Annual Report Genio CLG January - December 2016





Transforming Social Services Specialists in working with government and philanthropy to support people in leading self-determined lives

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## Foreword

Genio has been working with Government and philanthropy since 2008 to transform social services in a way that supports people to live self-determined lives. We have developed a model for public-private partnership (see page. 8) which consists of three stages; (i) early innovation; (ii) scaling innovation; and (iii) system-wide change.

Genio has disbursed almost €24m in innovation funding to 226 projects around Ireland to date through open competition, the majority of which represented Irish government innovation funding allocated by the Health Service Executive Ireland (HSE) and some funding from the Atlantic Philanthropies. As a result of this funding a further €31.3m has been reconfigured towards reforming services within the projects supported. To date projects have provided over 6,900 people with individualised supports in the community. In addition 12,800 individuals, families, carers and staff have received information and training through the projects we support.

"Working with Genio and seeing the very positive improvements in the development of services, has meant a huge amount because ultimately it keeps bringing the focus back to the needs of the individual, the needs of the person. Whenever I find myself a bit demoralised by all the bureaucracy, that is part of my work I find myself thinking about the end users and the reasons why we're here and working with Genio and philanthropy." Bairbre Nic Aongusa, Assistant Secretary, Department of Rural and Community Development.

Genio is currently working in stage two, the 'scaling innovation' phase, across our current programmes - dementia, mental health and disability. In this phase of work we are working with the Health Service Executive to support the refocusing of public resources to reach many more people and embed changes within the public system. This includes the development of the Service Reform Fund for mental health and disability;

"The Service Reform Fund is a dedicated piece of funding targeted at initiatives that can demonstrate that innovation and service reconfiguration benefits service users and also ensures resources are used to better effect." Yvonne O'Neill, Head of Planning, Performance and Programme Management, National Mental Health Division, HSE.

We believe that the Genio model has potential application in other social service areas in Ireland and in other countries. We look forward to sharing our learning and exploring further opportunities to ensure many more vulnerable people have the opportunity to lead selfdetermined lives in the community.



Shay Garvey Chairperson



Madeleine <u>Clarke</u> **Executive Director** 

Shay Garvey Waslelon Clock

#### Our vision

■ A society that benefits by valuing all of its citizens.

#### Our mission

 To provide opportunities that ensure people who are disadvantaged lead self-determined lives in their communities.

#### Strategic objectives

- ⇒ Innovation Funding to release funds to encourage innovation and costeffectiveness. These funds are outcome-focused and performance-managed.
- **Capacity Building** to support and capacity build key stakeholders to manage and implement service transformation.
- **•** Measuring Impact to undertake and commission research to measure impact.

# ABOUT GENIO

"Genio began by consulting with the people for whom change matters most. People who really need service and their families, their carers and their advocates. It became clear that people just want the lives that you and I want, they want to be able to make the choices that you and I make. They don't want something that's spectacular or elaborate."

Madeleine Clarke, Founding Director, Genio.

#### Background

Genio is a pioneering non-profit organisation specialising in social service transformation. It was established in Ireland in 2008 by Madeleine Clarke, Founding Executive Director.

"The motivation to establish Genio grew out of my experience of meeting people who were challenged in a number of different ways, who need good services to live the lives that they want to live. That includes people with disabilities, people with mental health difficulties, vulnerable children, people who are homeless; a whole range of people in our society who are dealing with adversity."

#### The challenges we face

Our challenge is to support the transformation of social services so that people are enabled to lead self-determined lives in the community.

#### Challenges worldwide

Governments invest significant resources every year in an effort to provide support to those in need, but there are increasing numbers of people dependent on social services and costs are rising. There has also been a significant shift in citizens' expectations of social and public services in recent years. People want services that are flexible and personalised to their needs while also expecting more cost-efficiency and value-for-money (Accenture, 2012).

Evidence shows that personalised, targeted social services achieve better outcomes for people than standardised, 'one-size-fits-all' approaches. Personalised services put the person at the heart of service design and delivery. It means giving people what they need, when and where they need. These types of services have also proven to be more cost-effective and sustainable (Accenture, 2012; McConkey et al., 2013).

However, transforming large scale social services is very challenging. As governments continue to fund legacy services, the gap in funding required by social systems continues to grow with the increase in the numbers of people living into their eighties and nineties and fewer people working. By 2025 it is estimated that the shortfall in the UK will be USD 170bn; in France, USD 100bn; in Germany, USD 80bn; in Italy, USD 30bn and USD 940bn in the US (Accenture, 2012).

Meanwhile, private investors and philanthropists interested in improving the lives of those who are disadvantaged often fund the development of good services. However, their hopes that these will be adopted and mainstreamed on the basis of proven success alone have generally been shown to be overly optimistic.

#### Challenges in Ireland

In Ireland we have traditionally invested in group-focussed, one-size-fits-all responses, which have left thousands of people living apart from their families and communities; many in institutions and group homes with little choice or control over their own lives.

Social services in Ireland are very complex. For historical reasons, they are delivered by a large network of non-governmental organisations. The number of stakeholders and the complexity of the relationships is a key challenge for government in transforming services.

Government services also have faced significant financial challenges over the past few years due to resource constraints, reductions in funding and the implementation of saving targets. This challenge comes at a time when expectations and demand for services is increasing every year along with costs. The population is now at its highest level since 1861 and will likely increase beyond 5 million by 2026 and beyond 6 million by 2046 (CSO, 2013). Life expectancy has increased with an expected increase of chronic disease by 40% by 2020 (IPH, 2010).

Government and government agencies have responsibility for spending public funding wisely, so with finite resources locked into the current way of providing services, there is little funding available to innovate.

In many cases third parties, such as NGOs and philanthropic organisations, try to innovate and change things from the outside by doing short term projects that may be successful for three to five years and then disappear. There is often an expectation that government will get on board once all the decisions have been made, which very often, doesn't work. There needs to be a sense of co-creation from the outset.

#### Meeting the challenges

Genio is meeting the challenges of transforming social services by working with Government and philanthropy from the outset to support people in leading selfdetermined lives. This requires social services to become personalised and cost-effective rather than standardised, 'one-size-fits-all' and unnecessarily expensive. Personalised services respond in timely and flexible ways that put the person at the heart of service design and delivery. It means giving people what they need, when and where they need it.

## What do we mean by personalised supports?

Personalising services means giving people what they need, when and where they need it; putting the person at the heart of service design and delivery. They have the following characteristics:

- Planned and delivered on the basis of a consideration of their wider needs and the potential contributions of each person, moving away from a focus on deficits.
- A response to individuals rather than group-based response.
- Chosen by the person with a disability, mental health difficulty or dementia (or their family or advocate as appropriate).
- Delivered in the community, fostering inclusion, and participation rather than in segregated, stigmatising settings.
- Inclusive of family and community supports and mainstream services.
- Reliant on paid professionals only when appropriate.
- Cost-effective and representing good value for money.

# **Public Private Partnership for System-wide Change**

Early Innovation to System-wide Change



**Stage one** is co-financed by Government and private funders (philanthropy and/or social investment). Outcomes to be achieved are clarified. Baseline evidence of current outcomes and costs is gathered. Open competition identifies early innovators who are awarded seed funding and offered training and support. Progress is closely monitored. Consumer awareness is raised as they see what 'better' looks like. Learnings are identified and shared to inform next stage.

Stage two private funding is a catalyst for increased refocusing of public resources. Better, cost-effective outcomes are achieved. Targeted competition identifies service reform initiatives that scale to reach more people and embed within public system. Training continues and early innovators are supported to become leaders for change. Consumer confidence increases. Progress is monitored and feedback loops continue to inform scaling process.

**Stage three** public funding is substantially refocused to achieve system-wide change. Innovative practice becomes mainstream. Private funding can continue to support consumer demand for better goods and services, which in turn drives supply. Continued monitoring and feedback informs and sustains progress.

# About Genio

In order to create this transformation in services, philanthropic funding is required to enable the system to innovate and take risks that would not be possible with tax payers money. It means that programmes, if successful, can be grown and scaled over time. Once the change becomes mainstreamed and is owned by government and by those providing services, philanthropy can step back or exit having achieved long-term impact across a wide population of people in need.

Genio works alongside government and philanthropy; forging collaboration and bringing experience and expertise to the change management process.

## We help to bring about change in three ways:

- Innovation Funding: Release funds on a competitive basis to encourage innovation & cost-effectiveness. These funds are outcome-focused and performancemanaged.
- 2. Capacity Building: Support and capacity build key stakeholders to manage and implement required changes.
- 3. Measuring Impact: Undertake and commission research to measure impact.

#### Genio model

We have developed a model for publicprivate partnership to achieve social service transformation. We take a phased approached across three stages; (i) early innovation; (ii) scaling innovation; and (iii) system-wide change.

#### Structure & governance

Genio Limited by Guarantee is an Irish registered company (Reg no. 454839) established in March 2008. It is governed by the Genio Board of Directors and operates as a non-profit organisation. Board Directors are normally elected for three-year terms and meet at least four times a year. The Board is supported by a board committee structure including the Finance, Audit and Risk Committee; Nominations and Successions Committee; Remuneration Committee; and Fund Development Committee.

Authority is delegated on a day-to-day basis to the Executive Management team and Executive Director of the company.

Genio established a charitable trust in 2010 called the Genio Trust in order to receive and disperse innovation funding. The Genio Trust is a registered charity (CRA 20075606, CHY 19312) which is governed by the Genio Trustees (*See Genio Trust Annual Report*).

#### Conflict of interest

The Board Directors are required to disclose all relevant interests and register them with the Executive Director and in accordance with company policy, withdraw from decisions where a conflict of interest arises.

#### **Board of Directors**

- Shay Garvey (Chair), Founding Partner, Frontline Ventures.
- Teresa Kilmartin (Company Secretary), Director, Symbio HR Solutions.
- Madeleine Clarke, Founding Director, Genio; Chair European Venture Philanthropy Association (EVPA).
- Dr Cathal Coleman, Adjunct Lecturer, NUI Maynooth and Open University.
- Brian Dunnion, Strategy Consultant.
- David McNamara, Chairman, Incol Funding Ltd; Director, Fonthill Private Equity Ltd.
- Dr Iognáid (Iggy) O'Muircheartaigh, Uachtarán/President Emeritus, NUI Galway.
- Geraldine Ruane, Chief Operating Officer, Trinity College Dublin.
- Barney Whelan, Former Director of Communications and Corporate Affairs, An Post.

The board of directors give their time on a voluntary basis. Total expenses paid to the Board of Directors in 2016 amounted to less than  $\in 1,000$ .

#### Our people

In 2016, Genio had a team of 15 Employees (6 part-time). See Appendix 1 for details of our current boards, committees and team.

Salary range:

€60,000 & under	10
€60,000 - €70,000	1
€70,000 - €80,000	1
€90,001 - €100,000	2
€110,001 - €120,000	1

#### **Principal office**

19-21 Westland Square, Pearse St., Dublin 2.

#### **Books of account**

The measures that the directors have taken to ensure compliance with Section 281-285 of The Companies Act 2014, are the utilisation of appropriately qualified accounting personnel and the maintenance of computerised accounting systems. The books of account are maintained at the company's Principal Office (See Appendix 2 for Genio Ltd. accounts).\*

#### Auditor

In accordance with Section 383 (2) of The Companies Act 2014, Deloitte, Chartered Accountants and Statutory Audit Firm have audited the Genio accounts since July 2010.

#### **Risk management**

Our Risk Management Policy requires that we do a full risk assessment each year. This means identifying the organisational risks and putting measures in place to avoid, minimise or mitigate our main risks.

This process will be repeated annually, reviewed by the Finance, Audit and Risk Committee and approved by the Board. The responsibility for the management and control of Genio rests with the Board and their involvement in the key aspects of the risk management process is essential, particularly in setting the parameters of the process and reviewing and considering the results.

\*The Genio Trust accounts are published in the Genio Trust Annual Report 2016.

The

Philanthropies

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ATLANT

Partners & affiliates

Feidhmeannacht na Seirbhíse Sláinte Health Service Executive







Jonathan Latten and Andy Parsons, Moving Home Project, Sligo

# INNOVATION FUNDING

"Philanthropy can be hugely helpful to policy makers like me who are in the process of trying to get change in social services because philanthropy can help to provide small amounts of funding which can enable service providers and policy makers to take risks which they otherwise would not feel able to do with tax payers' money"

Bairbre Nic Aongusa, Assistant Secretary, Department of Rural and Community Development We award innovation funding, the majority of which is government funding combined with some philanthropic support, to help bring about social service transformation. Funding is allocated on a competitive, performancemanaged basis to service providers to cover additional costs (similar to 'bridging finance') of moving from older models of service delivery to new models which are more costeffective and produce better outcomes.

## As part of the Genio model there are three stages of innovation funding:

Early Innovation: open competition identifies early innovators who are awarded seed funding and offered training and support. Progress is closely monitored.

**Scaling Innovation:** targeted competition identifies service reform initiatives that scale to reach more people and embed within public system.

System-wide Change: innovative practice becomes mainstream. Private funding can continue to support consumer demand for better goods and services, which in turn drives supply.

Genio has disbursed almost €24m to projects around Ireland to date through open competition, the majority of which represented Irish government innovation funding allocated by the Health Service Executive Ireland (HSE) and some funding from the Atlantic Philanthropies. This in turn leveraged a further €31.3m in additional resources which have been reconfigured within the projects supported. This reconfiguration of resources is critical to, not only the sustainability of the innovation we support, but also scaling transformation within the system without relying on on-going private funding. This funding represents stage one, the 'early innovation' phase, of our work

in dementia, mental health and disability (see the Genio Model).

To date, 226 projects have been awarded funding nationally to provide over 8,053 people with individualised supports in the community. In addition, 12,800 individuals, families, carers and staff have received information and training through the projects we support.

Genio is currently working in stage two, the 'scaling innovation' phase, across our current programmes. In this phase of work we are using innovation funding as a catalyst for increased refocusing of public resources to reach many more people and embed changes within the public system. We continue to work in collaboration with Government and the Atlantic Philanthropies. We are now supporting the establishment of a 'Service Reform Fund' (SRF) of €45m with the HSE to scale the reforms demonstrated over the past five years in disability and mental health services and to bring about systemic change in these areas.

#### Dementia Programme

We are working with government and philanthropy to meet the challenges in dementia through the HSE & Genio Dementia Programme. The aim of the programme is to ensure people with dementia continue to lead self-determined lives at home connected to their family, neighbours and community for as long as possible. The programme involves developing and testing a range of personalised, flexible and responsive supports and services. This work is aligned with government policy and supported by The Atlantic Philanthropies.

## By the numbers 2010 – 2016

1,292 Applications received

#### **226** Approved projects

## 8,053

People to receive personalised services

## 12,800

Individuals, family members & staff received training & information through the projects we support

## 5,200

People reached through events, conferences & other public forums

## €23.7m

Innovation funding awarded

## €31.3n

Further resources unlocked through supported projects

## 11

Mental health residential units closed Disability institutions closed

4

#### Early Innovation in Dementia 2011 - 2016

To date €4.9m innovation funding has been awarded to 13 dementia projects around Ireland in partnership with the Health Service Executive Ireland (HSE) and the Atlantic Philanthropies.

Projects in the Dementia Programme are led by multi-stakeholder Dementia Consortia and focus on reaching individuals across wider geographic and catchment areas. Consortia include people with dementia, families and carers, mainstream organisations and community groups, older people's services, hospitals and nursing homes.

Community-based supports for people with

dementia: Nine community-based projects are being supported through the programme between 2012 - 2017 across broad geographical areas in Ireland. These projects are developing a range of services and supports that are determined by the needs and preferences of people with dementia from early to more advanced and complex stages. In addition a tenth project received funding to develop and share online films to promote positive cognitive health behaviours, educate and combat the stigma associated with dementia and other degenerative brain diseases.

Transition between hospital and the community: This element of the programme focuses on the acute hospital sector. Three projects are developing integrated care pathways (ICP) for people with dementia so that access to and discharge from hospital is as seamless as possible, and that their experience is as good as it can be. Some of the work being undertaken by the hospitals include staff awareness-raising and education; environmental changes; enhanced integration of services; and process improvements.

#### Live projects

(January - December '16)

There are currently 4 projects underway within the Dementia Programme. These projects were awarded funding in 2013 with project durations of 2 years and 3 years. The two main streams of work are:

## (i) Integrated care pathway in the acute sector (2013)

There are three projects undertaking this work - St. James's Hospital (SJH); Mercy University Hospital Cork; Connolly Hospital and Dublin North West Local Health Office.

- Catchment areas of North & South Dublin and Cork.
- 5,201 people reached through education and awareness raising to date.

## (ii) Individualised supports for persons with complex needs (2013)

There were five projects undertaking this work - Louth Age Friendly Dementia Consortium; Carlow / Kilkenny Service Providers Forum; Mallow Crystal Consortium; Roscommon Dementia Friendly Community Group; Leitrim Day Hospital Consortium. The Mallow Crystal Consortium project is still active. In total to date, the five projects have provided:

- **279** people with dementia supported.
- 578 carers/family members supported.
- 29,928 HSE home support hours were delivered in a personalised way.
- 9,886 additional support hours were provided.
- 759 hours of training and education delivered.
- 49 people making use of assistive technology.

## Scaling Innovation in Dementia 2016 -2019

This element of the dementia programme represents the 'scaling phase' of our work in dementia (see the Genio Model) and is supporting the implementation of Intensive Home Care Packages (IHCPs) for people with dementia. A Home Care Package is a set of services provided by the HSE to help an older person to be cared for in their own home. Services provided through an Intensive Home Care Package are flexible, but might include home support hours, nursing care, physiotherapy, respite care etc. to support the person with dementia's needs. Genio is supporting the HSE with the implementation of personalised IHCPs, which includes sharing learning from the experience around the country of implementing IHCPs for people with dementia and enhancing the integration of services. Genio has also been commissioned by the HSE to carry out a research study on the implementation and impact of IHCPs for people with dementia.

#### Mental Health Programme

We are working with government and philanthropy to meet the challenges in mental health by supporting the development of recovery-based, cost-effective, personalised services that enable people with mental health difficulties to live as included and valued members of the community. This involves a move away from traditional, often expensive, services which group and segregate people focussing on their deficits rather than their strengths.

Recovery is about living as full and valued a life as possible while experiencing mental health difficulties. By putting recovery as the guiding principle of services, each person is supported on their journey towards an independent, self-directed life, centred on strengths, solutions, health and wellness.

## Early Innovation in Mental Health 2010 - 2015

To date €8m innovation funding has been awarded to 103 mental health projects around Ireland in partnership with the Health Service Executive Ireland (HSE) and the Atlantic Philanthropies.

#### Live projects

(January - December '16)

There are currently 5 mental health projects underway supporting 466 individuals around the country. These projects were awarded funding in 2013 and 2014 with project durations ranging from one to three years. The two streams of work are:

#### Supporting Recovery

- 3 projects
- 238 people

#### Supporting Work, Education & Training

- 2 projects
- 228 people

## Scaling Innovation in Mental Health 2016 - 2018

The Service Reform Fund (SRF) has been created by the Department of Health, the Health Service Executive (HSE) and the Atlantic Philanthropies in collaboration with Genio to implement mental health and disability service reform in Ireland. These reforms will focus on ensuring that personcentred and recovery-oriented services and supports are embedded, in line with government policy. This represents the 'scaling innovation' phase of our work in mental health (see the Genio Model).

SRF funding is open to applicants from each of the nine national HSE Community Healthcare Organisations (CHO). The SRF is working closely with representatives from each of these organisations, who have been invited to develop proposals for reform in their areas.

#### Priority areas for reform

Successful proposals to the SRF will focus on the four key areas below and will look outside of the mental health service into communities, the voluntary sector, and other mainstream organisations, to form alliances which will effectively support the reconfiguration of services.

- Advancing Recovery
- Employment Supporting Individual Placement and Support
- Community based living Transitioning from HSE provided accommodation
- Homelessness Supporting the mental health needs of individuals who are homeless during transitions to housing arrangements

In June 2016, the 9 CHOs and the National Mental Health Forensic Services began the process of developing proposals to enhance their internal capacities to plan and project manage service reform. Initial consultations took place with service users and Mental Health non-profit organisations to consider how best to reconfigure the services which they operate to promote a recovery focus with self-direction at the centre. Proposals were submitted in August and assessed by an SRF grants committee which included staff from the HSE and Genio, service users and family representatives. Following a number of rounds of feedback and critique, grants were made ranging in scale from €40,000 to €130,000.

These resources will be used to consult with stakeholders; analyse existing capacities and areas of weakness in services; and to develop robust reform plans which will then be submitted in mid-2017. This second round of funding will enable Mental Health services to move away from funding more traditional group-based, medicalised services towards more recovery focused, self-directed services. Approximately, €10m will be allocated in this second round. All proposals will be submitted in 2017 through the CHOs and will be evaluated against criteria agreed by the SRF partners. Funding is targeted specifically at sustainable reform and reconfiguration of services. The HSE and Genio will be collaborating closely on this work.

#### **Disability Programme**

We are working with government and philanthropy to meet the challenges in disability by supporting the development of cost-effective, personalised services that enable people with disabilities to live as included and valued members of the community. This involves a move away from traditional, often expensive, services which group and segregate people, often focussing on their deficits rather than their strengths. Personalised services means putting the person at the heart of service design and delivery, giving people what they need, when and where they need it.

#### Service Reform Funding January 2016 - December 2016

Funding was awarded in December 2016 through the Service Reform Fund for Mental Health to each of the nine national HSE Community Healthcare Organisations (CHO). Funding ranged in scale from  $\leq$ 40,000 to  $\leq$ 130,000. These resources will be used to consult with stakeholders; analyse existing capacities and areas of weakness in services; and to develop robust reform plans which will then be submitted in mid-2017. Further funding will be awarded in 2017 based on these proposals.

Organisation	Location	Funding awarded
CHO 1	Donegal, Sligo/Leitrim/West Cavan and Cavan/ Monaghan	€130,000
CHO 2	Galway, Roscommon and Mayo	€120,000
CHO 3	Clare, Limerick, and North Tipperary/East Limerick	€110,000
CHO 4	Kerry, North Cork, North Lee, South Lee, and West Cork	€120,000
CHO 5	South Tipperary, Carlow/Kilkenny, Waterford and Wexford	€130,000
CHO 6	Wicklow, Dun Laoghaire and Dublin South East	€40,000
CHO 7	Kildare/West Wicklow, Dublin West, Dublin South City, and Dublin South West	€120,000
CHO 8	Laois/Offaly, Longford/Westmeath, Louth and Meath	€110,000
СНО 9	Dublin North, Dublin North Central and Dublin North West	€110,000
National Forensic Mental Health Service	Dublin	€45,000
basis c	l be released in 2017 on the of progress achieved over the <b>Total</b> course of the funding period.	€1,035,000





Service Reform Fund Disability & Mental Health



## Early Innovation in Disability 2010 - 2015

To date €10.8m innovation funding has been awarded to 110 disability projects around Ireland in partnership with the Health Service Executive Ireland (HSE) and the Atlantic Philanthropies.

#### Live projects

#### (January - December '16)

There are currently 10 disability projects underway supporting 216 people around the country. These projects were awarded funding in 2012 and 2013 with project durations ranging from one to three years. The three streams of work are:

#### Integrated Community Living

- 8 projects
- 184 people

#### Alternative Respite

- 2 projects
- 32 people

## Scaling Innovation in Disability 2016 - 2019

The Service Reform Fund (SRF) has been created by the Department of Health, the Health Service Executive (HSE) and the Atlantic Philanthropies in collaboration with Genio to implement mental health and disability service reform in Ireland. These reforms will focus on ensuring that personcentred and recovery-oriented services and supports are embedded, in line with government policy. This represents the 'scaling innovation' phase of our work in disability (see the Genio Model). Within the Service Reform Fund for disability there are two strands. The first is a targeted and accelerated change programme working with 10 congregated sites. The focus of this work is to build self-directed, community based services for the people living in these congregated settings. In 2016, initial site visits, meetings and capacity building took place. Draft proposals for innovation funding were prepared by each site. In 2017, further capacity building will take place and a first tranche of funding will be awarded to successful applicants.

The second strand will be a competitive grants round in 2017 targeted at supporting person-centred approaches to community living, reform of day services and alternative respite services.

All proposals will be evaluated against criteria agreed by the SRF partners. Funding is targeted specifically at sustainable reform and reconfiguration of services. The HSE and Genio will be collaborating closely on this work.

#### Projects supported by the Genio Trust 2010 – 2016

Since 2010 Genio innovation funding has been awarded to 226 projects across Ireland in disability, mental health and dementia



SSDL Practioner training with Hope Leet Dittmeier and participants

# CAPACITY BUILDING

Supported Self-Directed Living (SSDL) is central to our capacity building programme. SSDL occurs when an individual, with the right support, is able to choose, pursue and achieve a "good life", to a similar extent to other people in society. We provide training, information and expertise to individuals, families, service providers and others who have a role to play in supporting people who are disadvantaged to live full lives in their communities.

As part of the Genio model, there are three stages of capacity building:

- Early Innovation: projects are offered training and support. Consumer awareness is raised as people see what 'better' looks like.
- 2. Scaling Innovation: training continues and early innovators are supported to become leaders for change. Consumer confidence increases.
- 3. **System-wide Change:** Innovative practice becomes mainstream. Private funding can continue to support consumer demand for better goods and services, which in turn drives supply.

#### Formal training

#### Supported Self-Directed Living (SSDL)

Over the past six years Genio has developed a range of training courses in Supported Self-Directed Living (SSDL) approaches. We continue to work closely with SSDL participants and to respond to their feedback in order to improve our courses each year.

#### What is SSDL?

Supported Self-Directed Living (SSDL) is central to our capacity building programme. SSDL occurs when an individual, with the right support, is able to choose, pursue and achieve a "good life", to a similar extent to other people in society. A number of approaches have been found to contribute towards the achievement of SSDL, the most prominent being 'Independent Living', 'Recovery', 'Social Role Valorisation' and 'Person-centred Dementia Care'. Whilst these various approaches adopt somewhat differing focuses and frames, they share in common a powerful commitment to facilitating good life outcomes for people, as well as an ability to demonstrate effectiveness in bringing about such outcomes.

SSDL training programmes which ran throughout 2016:

- SSDL 15 Day Practitioner Programme (42 participants)
- SSDL 10 Day Programme for Accelerated Sites 2016 (31 participants)
- SSDL Introduction to senior management for Accelerated Sites 2016 (10 participants)
- SSDL 4-Day Train the Trainers (16 participants)
- SSDL 1-Day Family Leadership (85 participants)

#### SSDL Programmes 2017

In 2016 we spent time listening to the issues people encounter in implementing SSDL approaches. We learned that there continues to be a growing need for more intensive, practice-based training, and to provide shorter, more customised training specifically for family members and senior leaders. In light of this we are facilitating a range of training programmes throughout 2017:

#### SSDL Practitioner Training A 14 day training course for frontline staff, supervisors & managers.

SSDL Disability Change Exchange

A series of one day learning events is aimed at experienced SSDL practitioners who are interested in sharing their experiences of implementation and deepening their learning.

#### SSDL Family Workshops - Striving for Valued Lives

A series of one-day workshops for family members of individuals who are engaged in, or interested in, developing a good life for their family member.

#### SSDL course accreditation

At the end of 2016 we received accreditation from Athlone Institute of Technology at QQI Level 6 standard for our SSDL 14-day practitioner training programme

## Collaborative learning and practice development

Service Reform Fund (SRF) Disability Capacity building for 10 accelerated sites (see page 20 for more details)

- Sth April SRF Leadership Event (80 participants) aimed at key Finance and HR staff to explore strategies and challenges associated with reconfiguring resources.
- 26th May SRF Finance Workshop (50 participants) - aimed at leaders from each of the 10 sites to explore theory of practice and implementation strategies.

#### **Dementia Learning Network**

The Genio Dementia Learning Network has developed organically since 2012, initially based around project consortia, but now encompassing a wider constituency who are keen to learn about new ways of supporting people with dementia and their families. There are approximately 1200 members in the wider learning network. During the initial three years of the dementia programme there were also several communities of practice with about 10-15 members each who had a high level of engagement and contributed to the early learning of the programme. 38 events have been organised, ranging from national conferences with 200+ attendees, to expert facilitated workshops with an average of 20 attendees to communities of practice with an average of 8 attendees. These events were tailored to specific learning needs and learning outcomes and accompanying resources have helped to enhance and embed the learnings and share it with the wider network.

A wide range of resources have been produced to synthesise learning and support the work of the Dementia Learning Network, including learning papers, briefing papers, podcasts, films and presentations. To optimise dissemination, a section of the Genio website was devoted to the Dementia Learning Network <u>www.genio.ie/dln.</u>

#### HSE & Genio Hospital Briefing Event

We were delighted to welcome over 120 delegates to the HSE & Genio Dementia Briefing 2016 'Integrated Pathways of Dementia Care in Action - Early Learning from Three Acute Hospitals in Ireland' on Wednesday 14th December in Dublin. As part of the HSE & Genio Dementia Programme three hospital projects (St. James's Hospital, Mercy University Hospital and Connolly Hospital) are developing integrated care pathways for people living with dementia to support planned and appropriate access to acute services; to improve their experience while in hospital; and to support their discharge back to the community.

The briefing provided an opportunity to learn from these pioneering projects and marks the mid-way point in a three year programme. Representatives from the three hospitals including Professor Brian Lawlor (St. James's), Dr Suzanne Timmons (Mercy) and Dr Siobhán Kennelly (Connolly) shared early learnings from the projects outlining the challenges they have encountered, the responses that have been developed and how these initiatives are impacting service delivery for people living with dementia.

The event was opened by Madeleine Clarke, Founding Director of Genio who acknowledged the innovative and often challenging work being undertaken by the three projects - "Bringing about change in any setting is challenging but in hospital settings it's particularly complex".

Michael Fitzgerald, HSE Head of Operations and Service Improvement for Older People, discussed the challenges faced by people with dementia and their families within the health service and the National Dementia Strategy which was launched last year to address the development of appropriate services. He went on to say that "without the flair and flavour Genio brings to our thinking we'd be far worse off and I'm not sure it would always happen...we need that as a facilitator within our services." Dr Fiona Keogh, Genio Director of Research and Evidence set the context of the programme while Dr Anne Marie Brady from the School of Nursing & Midwifery, Trinity College Dublin presented initial findings from an evaluation of the programme which will continue until 2018 when a final report will be published.

One of the highlights of the event was a moving and powerful presentation from Hazel Luskin Glennon who spoke about her own personal experience of navigating the hospital system with her husband Brendan who had dementia. Her story set a strong context for the work that these three hospitals are now undertaking to ensure better experiences and outcomes for people with dementia and their families.

The event was chaired by Dr Siobhán O'Halloran, Chief Nursing Officer, Department of Health and Dr Colm Henry, National Clinical Advisor and Programme Lead for Acute Hospitals, HSE. Louise Murphy and Natalie Cole, DemPath project St. James's Hospital Dublin

# MEASURING IMPACT

"Evaluation demonstrates that this is beginning to bring about dramatic improvements in the lives of service users while generally doing so in a costneutral or more cost-effective way."

Martin O'Brien, Former Senior Vice President, The Atlantic Philanthropies Genio places a high priority on being accountable and on providing independently measured impact. Since 2008 we have spent over €2m on research and evaluation, much of which has been undertaken by researchers at universities and research institutes. In addition, we have developed a comprehensive monitoring and evaluation system to extract and collate the learning from all projects funded through Genio.

Our focus is on producing findings that demonstrate the impact on people's lives and services; and that help inform key decision makers in allocating resources and budgets to best effect. To date we have invested over €2m in commissioning independent studies across our programme areas.

As part of the Genio model there are three stages of work within the Research Programme:

- Early Innovation: outcomes to be achieved within each programme area (e.g. disability, mental health, dementia) are clarified and baseline evidence of current outcomes and costs are gathered. Learnings are identified and shared to inform the next stage.
- Scaling Innovation: progress is monitored and feedback loops continue to inform the scaling process - this represents the current work in our three programme areas.
- System-wide Change: continued monitoring and feedback will inform and sustain progress with each area.

#### Commissioned research

We commission independent research, overseen by topic specific Research Expert Panels, in areas such as moving to independent living and community-based dementia supports. This programme is dynamic and responsive to opportunities which arise within our work. Findings from this research are disseminated to service commissioners, policy makers and used to inform advocacy and to refine our funding process.

We also commission briefing papers to provide accessible overviews of key areas relating to the development of disability, mental health and dementia services.

#### Some key publications from 2016:

#### Economic Analysis of a Community-Based Model of Dementia Care

Authors: Prof Eamon O'Shea and Christine Monaghan, National Centre for Social Research on Dementia, National University of Ireland Galway (NUIG)

The report describes the results of an economic analysis of the first four sites in the HSE & Genio Dementia Programme. The objective of the current study is to provide an economic analysis of the cost of care for people with dementia on the boundary between home care and residential care within the innovative HSE & Genio Dementia Programme. A cohort of people with dementia were identified who were living at home, but were at significant risk of admission to residential care in the medium term. By concentrating on the margin between community and residential care, it may be possible to provide some insight into the benefits of investing in personalised community-based supports for this group rather than the alternative of admission into long-stay care.

#### Key findings:

- Significant numbers of people with dementia could be supported at home for longer.
- This would result in savings to the exchequer.
- 32% of the people with dementia in this study were at risk for nursing home admission. Their care in the community cost significantly less than care in a residential setting.
- For a relatively small investment in innovative, personalised supports, lives can be transformed and residential costs postponed.

The report is published here: <u>www.genio.ie/</u> <u>economic-analysis-dementia</u>

## Community Supports Model for People with Dementia

Research team: HSE and Genio

This publication from the Health Service Executive & Genio is the first comprehensive Community Supports Model for People with Dementia in Ireland. Although informed by international learning, this model is a unique Irish innovation and draws from the experience of four key demonstration projects undertaken across Ireland from 2012-15. The focus of this work has been on dementia, but the learning from the model also has potential for all older people's services and other service areas in Ireland and internationally.

#### Key findings:

 Community-based supports represents a feasible model to avoid or delay residential care, allowing people with dementia to live fulfilling lives in their community.

- This approach puts people with dementia and their families at the centre of service design and works with wider community, health and social care services.
- The community supports model offers good value for money, especially when compared with residential care.
- This service design process has identified the key components of a comprehensive Community Supports Model that can act as a catalyst for change, and apply at scale in Ireland.

The report is published here: <u>www.genio.ie/</u> <u>community-supports-model</u>

## How personal budgets are working in Ireland - A Research Brief

A PhD student has been funded by Genio through the Structured Population and Health-services Research Education (SPHeRE) Programme over four years to carry out an evaluation of the implementation of personalised budgets in four Genio-supported projects for people with a disability. The evaluation presents a summary of the main lessons learned according to the key people involved in these initiatives, including individuals with a disability who participated in the initiatives; family members; paid and unpaid advocates; and staff members from within the four organisations.

This document is aimed at anyone who is interested in the practicalities, successes and challenges of implementing individualised funding initiatives in Ireland.

#### Key findings:

- For personal budgets to work effectively, the focus should be on each person's abilities and interests, along with encouraging independence and personal responsibility.
- The process of implementing personal budgets must be clear and easy to access.
- Training for all parties is essential in order to access and utilise personal budgets effectively.
- Sharing stories and celebrating achievements via social networks, video and other media can highlight success and grow momentum.

The report is published here: <u>www.genio.ie/</u> <u>personal-budgets</u>

#### An evaluation of personalised supports to individuals with disabilities and mental health difficulties – follow up study

Authors: Prof. Roy McConkey and his colleagues in the Ulster University (UU), Trinity College Dublin (TCD) and National University of Ireland Galway (NUIG)

This evaluation is one of the most comprehensive studies of its kind in Ireland and internationally. 197 people with disabilities and mental health difficulties were included from 23 projects, as well as 102 relatives of these individuals and 187 key workers supporting the participants. The aim of this study was to provide the evidence required to inform the transition from traditional group-based models to individualised, cost-effective supports and services, and to accelerate the availability of such services and supports. The first round of findings from this longitudinal evaluation have been published at: www.genio.ie/UUevaluation-personalised-supports1.

A further data uplift by Prof. Roy McConkey and colleagues, Ulster University (UU) took place on this study in 2016, thus extending the follow-up period for this sample. This will enable the longer-term impact of a move to independent living to be established as well as the impact on those individuals who had only just moved at the end of the initial study. The results of this study will be made available in 2017.

#### Initial key findings include:

- Two-thirds of the participants in the initial study had moved to either personalised arrangements or to group homes with a further one-third awaiting relocation.
- Those who live in independent accommodation with personalised supports had greater control and choice in their lives, more community engagement and increased personal relationships compared to residents in group homes.
- Those remaining in congregated settings fared worst in relation to control and choice.
- Average staff costs were significantly higher in group homes than personalised arrangements.

#### Other Reports and Learning Papers Published

- Telecare and Assistive Technology Evaluation
  www.genio.ie/at-evaluation
- Inclusion of People with Dementia in the Design of Services <u>www.genio.ie/inclusion-service-design</u>
- Dementia Consortia: Integrated networks to deliver individualised supports for people with dementia and their family carers <u>www.genio.ie/dementia-consortia</u>

## Monitoring and evaluation undertaken by the Genio team

All projects receiving support from Genio are monitored and supported by our programme managers and receive at least two to three on-site visits annually throughout the life of the projects (more in some cases). Over the course of these visits quantitative and qualitative information is collected on the progress of the project overall (organisationally) and of the individual beneficiaries. Challenges and barriers are identified and addressed, and financial monitoring of expenditure against agreed budgets is also carried out.

We extract and collate the learning from projects and make it available in an accessible way with short, easy-to-read, practical learning papers focused on producing good outcomes for the person and the organisation.

Genio uses Goal Attainment Scaling (GAS) to capture and summarise the achievements of the projects we support. Goal Attainment Scaling (GAS) is an evaluation method which measures achievement relative to the set of goals and outcomes agreed with the projects. It allows achievements across a diverse range of projects to be compared while preserving the uniqueness of the activities and outcomes of each individual project.



Published reports can be found on the Genio website: www.genio.ie/ our-impact/researchevidence

To date, 158 completed disability and mental health projects have been scored, which generated the following results:

- 84% of projects to date have achieved or exceeded their project aims
- 16% of projects have not yet achieved all of their project aims

## Health and social services research and evaluation

The Genio team also undertakes health and social services research and evaluation. There are currently two major in-house research projects underway which will continue throughout 2017 and 2018:

- An evaluation of Intensive Home Care Packages (IHCPs) for People with **Dementia** Genio has been commissioned by the HSE to carry out a research study on the implementation and impact of IHCPs for people living with dementia Following an agreement between the Department of Health and The Atlantic Philanthropies, the HSE is providing up to 500 IHCPs for people with dementia across Ireland over three years, which commenced in January 2015. A key feature of the IHCPs is that they are to be tailored to the assessed needs and preferences of people with dementia and their family members, with the underlying aim of putting the person at the centre of the service and supporting them to remain at home for as long as possible. Genio research team: Dr Fiona Keogh, Dr Maria Pierce, Dr Padraic Fleming, Karen Neylon.
- Service Reform Fund Action Research Study The study is designed to inform the implementation of the Service Reform Fund's work and to surface learnings, opportunities and challenges on an on-going basis. Action Research by design engages participants to candidly look at what they say they do compared to what is currently being done. Reflection provides an impetus for change as participants come to identify gaps and recommendations for

service improvement that they wish to address. Problems that are identified are significant to the participants in their setting, therefore, planning and change processes are locally specific, to meet the needs of those in the setting. Participants, facilitated by the researcher, will create cycles of constructing, planning, taking action and evaluating for generating actionable knowledge to use for further cycles (Zuber-Skerritt and Fletcher 2007). Researcher: Dr Niamh Lally, Genio.

#### Upcoming reports 2017

- Analysis of innovative communitybased dementia services: investigation of value case. This study will carry out further analysis of a database that was developed to support detailed data collection in sites in the HSE and Genio Dementia Programme. The overall aim is to develop useful ways of capturing and presenting the rich array of innovative dementia services and supports implemented in two sites, and the value case for their continuation and further development Authors: Dr Kevin Cullen and Dr Richard Wynne, Work Research Centre. In progress – estimated completion late 2017.
- Evaluation of Integrated Care Pathways in Dementia Care. The overall aim of the evaluation is to understand how integrated care pathways (ICPs) and individualised supports in the community for dementia can change and improve service delivery and outcomes for people with dementia and their families. The study covers the progress of ICPs in three Irish hospitals; St James's Hospital; Mercy University Hospital; Connolly Hospital;

and the development of personalised supports in two community sites in Leitrim and Kilkenny. The evaluation is underpinned by an evaluation framework called RE-AIM. Using this framework, project activity is evaluated in terms of reach, effectiveness, adoption, implementation, and maintenance. Authors: Dr Annemarie Brady, Dr Geralyn Hynes, Dr Brian Keogh, Dr Louise Daly, Mr Brendan Kennelly, Dr Mairéad Bracken-Scally, Dr Aurelia Ciblis, Prof Mary McCarron, Trinity College Dublin. In progress - estimated completion date 2017.

An evaluation of novel and innovative respite services in intellectual disability services in Ireland. The current research sought to determine the differences between alternative forms of respite in Genio-supported projects and traditional respite in the form of a stay in a residential facility. A secondary aim was to examine the extent to which the nature of care as reflected in the services was associated with service users' and family carers' quality of life and experience of care. Authors: Dr Suzanne Guerin and Dr Philip Dodd, University College Dublin. Final analysis underway. Report due in 2017.

Michael Fitzgerald, Head of Operations and Service Improvement Services for Older People, HSE; Madeleine Clarke, Founding Director Genio; and Mary Manning, General Manager, National Dementia Office

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## APPENDICES

#### Appendix 1 - Genio Boards, Committees & Team 2016/17

Special thanks to those who work with us on our boards and committees which comprises national and international expertise provided on a wholly voluntary basis.

#### **Genio Board of Directors**

(Voluntary)

- Shay Garvey (Chair), Founding Partner, Frontline Ventures.
- Teresa Kilmartin (Company Secretary), Director, Symbio HR Solutions.
- Madeleine Clarke, Founding Director, Genio; Chair European Venture Philanthropy Association (EVPA).
- Dr Cathal Coleman, Adjunct Lecturer, NUI Maynooth and Open University.
- **S** Brian Dunnion, Strategy Consultant.
- David McNamara, Chairman, Incol Funding Ltd; Director, Fonthill Private Equity Ltd.
- Dr Iognáid (Iggy) O'Muircheartaigh, Uachtarán / President Emeritus, NUI Galway.
- Geraldine Ruane, Chief Operating Officer, Trinity College Dublin.
- Barney Whelan, Former Director of Communications and Corporate Affairs, An Post.

Finance, Audit & Risk Committee (Voluntary)

- Geraldine Ruane, Chief Operating Officer, Trinity College Dublin.
- Barney Whelan, Former Director of Communications and Corporate Affairs, An Post.
- David McNamara, Chairman, Incol Funding Ltd; Director, Fonthill Private Equity Ltd.

#### Genio Board of Trustees

(Voluntary)

- Prof Brian MacCraith (Chair), President of Dublin City University.
- Ruth Barrington , former Assistant Secretary, Department of Health and Children, Ireland.
- Geraldine Ruane, Chief Operating Officer, Trinity College Dublin.
- Barney Whelan, Former Director of Communications and Corporate Affairs, An Post.

#### Genio Team

(2017)

- ➔ Madeleine Clarke, Executive Director.
- Dr John Healy, Deputy Executive Director.
- Antoinette Mangan, Chief Finance Officer (P/T).
- Elaine Howard, Programme Manager -Dementia.
- Mary McGuire, Programme Manager -Dementia (P/T).
- Sharon Lane, Programme Manager Mental Health (P/T).
- Tara Doheny, Programme Manager Disability (P/T).
- Charlotte Knight, Capacity Development and Outreach Manager (P/T).
- ➔ Dr Maria Pierce, Research Manager.
- Dr Olivia Cosgrove, Information Manager (P/T).
- ➔ Karen Neylon, Research Assistant.
- ➡ Fiona Murphy, Communications Manager.
- ➔ Louise Place, Office Manager.
- S Elaine Gallagher Docherty, Administrator.
- Dr Fiona Keogh, Principal Investigator of Evaluation of Intensive Home Care Packages.

#### Appendix 2 - Genio CLG Accounts

#### GENIO COMPANY LIMITED BY GUARANTEE

#### STATEMENT OF INCOME AND RETAINED EARNINGS FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2016

	12 months ended 31/12/2016 €	18 Months ended 31/12/2015 €
INCOME	3,040,469	2,307,375
EXPENDITURE	(3,050,832)	(2,315,756)
DEFICIT ON ORDINARY		
ACTIVITIES BEFORE INTEREST	(10,363)	(8,381)
Interest receivable and similar income	1,820	488
DEFICIT ON ORDINARY ACTIVITIES BEFORE TAXATION	(8,543)	(7,893)
Taxation		
DEFICIT ON ORDINARY		
ACTIVITIES AFTER TAXATION	(8,543)	(7,893)
RETAINED EARNINGS AT THE BEGINNING OF THE REPORTING YEAR	5,465	13,358
RETAINED (DEFICIT)/EARNINGS FOR THE REPORTING PERIOD	(3,078)	(5,465)

#### GENIO COMPANY LIMITED BY GUARANTEE

#### BALANCE SHEET AS AT 31 DECEMBER 2016

	2016 €	2015 €
FIXED ASSETS		
Tangible assets	38,664	33,601
Intangible assets	38,664	33,601
<b>CURRENT ASSETS</b> Debtors: (Amounts falling due within		
one financial year)	484,158	25,770
Cash at bank and in hand	30,633	47,084
	514,791	72,854
<b>CURRENT LIABILITIES</b> Creditors: (Amounts falling due within		
one financial year)	(556,533)	(100,990)
NET CURRENT LIABILITIES	(41,742)	(28,136)
TOTAL ASSETS LESS		
CURRENT LIABILITIES	(3,078)	5,465
NET LIABILITIES	(3,078)	5,465
CAPITAL AND RESERVES		
Retained (deficit) /earnings	(3,078)	5,465

The financial statements were approved by the Board of Directors on 7 June 2017.

#### GENIO COMPANY LIMITED BY GUARANTEE

#### STATEMENT OF CASH FLOWS FOR THE FINANCIAL YEAR ENDED 31 DECEMBER 2016

1.	2 months ended 31/12/2016 €	18 months ended 31/12/2016 €
Reconciliation of deficit on ordinary activities	before	
interest to net cash inflow from operating act	vities	
Deficit on ordinary activities before interest	(10,363)	(8,381)
Depreciation	13,215	17,767
(Increase)/decrease in debtors	(458,388)	90,471
Increase/(decrease) in creditors	49,643	(43,816)
Net cash (outflow) / inflow (used in)/		
from operating activities	(405,893)	56,041
Cash flow from investing activities		
Interest and similar income received	1,820	488
Capital expenditure	(18,278)	(13,817)
Net cash flow from investing activities	(16,458)	(13,329)
Cash flow from financing activities		
Grant received	2,028,132	2,502,719
Grant released	(1,296,826)	(2,207,135)
Transfer from Genio CLG	(325,406)	(295,585)
Net cash flow from financing activities	405,900	(1)
Net (decrease)/ increase in cash and cash equivalents in the financial year	(16,451)	42,711
Cash and cash equivalents at the beginning of the financial year	47,084	4,373
Cash and cash equivalents at the end of financial year		47,084

#### Thank you

We would like to extend our thanks to the Department of Health, the HSE and the Atlantic Philanthropies for their continued support; to our Boards and Committees who continue to offer their expertise and time on a voluntary basis; and the many individuals, families, projects and organisations for their dedication and efforts to support people to lead selfdetermined lives in the community.



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