

In the Business of Smart Social Investment **About** Genio

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The Coming

Year

Annual Report 2014

July 2013 - June 2014



Genio is focused on demonstrating and scaling ways of personalising services (i.e. putting people who use services at the heart of their design and delivery). We work closely with the Health Service Executive (HSE) and Department of Health and are supported by the Atlantic Philanthropies. We recognise that while philanthropy has a vital role to play in supporting demonstration of good quality, cost-effective services, Government is best placed to sustain and scale services in the context of implementing policy and using public funds.

The Irish Government has, in the last decade, created far-sighted policies which reflect best international practice and set out how the care of people with disabilities and mental health difficulties should be moved from institutions to the community. (Future Health: A Strategic Framework for Reform of the Health Service 2012–2015 / National Disability Strategy Implementation Plan 2013 – 2015). However, there are many challenges involved in reconfiguring public spending to align practice with policy.

Given demographic trends and rising levels of unmet need it is particularly important to ensure that resources are used to best effect in the interests of those who require support now and in the future.

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Pat McLoughlin Chairman

Madeleine Clarke

Executive Director

#### Our vision

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

#### Our mission

To provide opportunities that ensure people who are disadvantaged receive the support they need to live full lives in their communities.

#### Strategic objectives

- Develop the capacity of key stakeholders to establish and sustain cost-effective individualised living options.
- Demonstrate how resources can feasibly be deployed to ensure individualised supports can be made available to those in need on a cost-effective basis
- Develop and disseminate a clear evidence-base in Ireland for how to deliver and resource cost-effective individualised supports.



Genio is an Irish non-profit organisation that works to bring Government and philanthropic funders together to develop better ways to support disadvantaged people to live full lives in their communities.

We work in partnership with the Department of Health and the Health Service Executive, supported by the Atlantic Philanthropies. Driven by a vision of a society that benefits by valuing all of its citizens, we believe that everyone should have opportunities to participate in communities that value their contributions, regardless of age, disability or other perceived disadvantage. So far we are working to improve the lives of people with disabilities, mental health difficulties and dementia and we are expanding into new areas where we can help reform services for those who in need.

#### Context for our work

There has been strong coherence in the goals and objectives of recent Irish policy which describe a similar service model for different sectors within the health and social care area. This model is strongly person-centred or individualised; is focused on enabling

people who need support to remain living in their own homes for as long as possible; and addresses the need to give more control to those using services, through involving the person in the design of the supports they need and in potentially controlling the funding for their supports. The common objectives across these policies are to improve quality of life, to enable people to achieve their full potential and to support those with disabilities, mental health difficulties, older people and others who need support to participate as active included citizens.

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

Release funds on a competitive basis to encourage innovation cost-effectiveness. These funds are outcome focused and performance-managed.

Support and capacity build key stakeholders to manage and implement required changes.

Measuring Impact
Undertake and commission
research to measure impact.

#### Smart Social Investment

Genio is demonstrating how change can be achieved through the strategic investment of funds in innovative projects which are effective, accountable and transparent. We call this Smart Social Investment. We recognise that private donors and philanthropists have a vital role to play in supporting the demonstration of good quality, cost-effective services to those in need. Government is best placed to sustain and scale services in the context of implementing national policy. Genio brings public and private interests together to achieve change and lasting impact that can be difficult, if not impossible, for either to achieve alone.

## The principles which guide our work

We believe that the needs of citizens should be the primary guide for the design of social services. The people who use these services often have insights and capacities to help Government shape provision in effective, innovative and cost effective ways. We are passionate about improving services so that they:

- → Reflect the priorities of the people being served.
- ➡ Enable limited resources to be targeted at the best and fairest value.
- ⇒ Foster independence, participation and community inclusion.
- Enable the formulation and implementation of progressive, democratically endorsed, public policy.

#### Our approach

As well as believing in a compelling vision for change, we are practical and realistic about how change within services happens. We focus in particular on those areas where:

- → There is a gap between well-designed policy and service user experience.
- Policy is being formulated and needs to be informed by how to get the best

- outcomes for people being served in the context of limited resources.
- Service providers can be assisted to achieve change.

We avoid proposing elaborately designed blueprints and instead focus on increasing access of service users and their families to cost-effective services within the context of a realistic interpretation of statutory obligations and demographic trends.

## What do we mean by individualised supports?

The emphasis in providing individualised supports is building on a person's strengths, responding to them as a citizen, and supporting them to have an ordinary life. Individualised supports have the following characteristics:



- → Planned and delivered on the basis of a consideration of the wider needs and the potential contributions of each person, moving away from a focus on deficits.
- → A response to each person rather than group-based response.
- Chosen by the person (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.

#### Structure & governance

Genio Limited 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, Executive Director and Chief Operations Officer 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 (CHY 19312) which is governed by the Genio Trustees. All members of Genio boards and committees give their time on a voluntary basis (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**

- → Pat McLoughlin, Chairperson, Genio; Former CEO, Irish Payment Services Organisation; Former Chairperson, Local Government Efficiency Implementation Group.
- Madeleine Clarke, Founding Director, Genio.
- Dr Cathal Coleman, Lecturer, Department of Politics, University College Dublin; IT Consultant.
- Teresa Kilmartin, Director, Symbio HR Solutions.
- → Patrick McGowan, Expert by Experience; Lecturer, Dublin City University; former Director of Advocacy, Irish Advocacy Network.
- Geraldine Ruane, Chief Operating Officer, Trinity College Dublin.
- Dr Iognáid (Iggy) O'Muircheartaigh, Uachtarán / President Emeritus, NUI Galway.
- Barney Whelan, Director of Communications and Corporate Affairs, An Post.

#### Our people

Genio currently has a team of 11 Full Time Employees (FTEs). See Appendix 1 for details of our boards, committees and team.

#### **Principal Office**

Marlinstown Office Park, Mullingar, Co. Westmeath, Ireland.

#### Books of account

The measures that the directors have taken to ensure compliance with Section 202 of the Companies Act, 1990, are the utilisation of appropriately qualified accounting personnel (Crowleys DFK) 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 160 (2) of The Companies Act, 1963, Deloitte, Chartered Accountants have audited the Genio accounts since July 2010.

#### Risk management

Our Risk Management Policy require that we do a full risk assessment each year. This means identifying the organisation 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.

#### Partners & affiliates





Feidhmeannacht na Seirbhíse Sláinta Health Service Executive

The

ATLANTIC

Philanthropies



A&L Goodbody











<sup>\*</sup>The Genio Trust accounts are published in the Genio Trust Annual Report 2013 - 2014.



Genio works in collaboration with the Department of Health, the HSE and the Atlantic philanthropies; along with service providers, individuals and families; to support projects which are improving the lives of thousands of people across Ireland.

Since 2010, we have awarded innovation funding (primarily Government innovation funding through the HSE) from the Genio Trust to 210 projects nationally to provide almost 5,500 people with individualised supports in the community. In addition almost 9,000 individuals, families, carers and staff have received information and training through the projects we support. We have awarded €23.6m in innovation funding to date which has unlocked a further €32.4m in resources through the projects we support.

#### Disability Programme

The aim of the Genio Disability Programme is to accelerate the availability of cost-effective, individualised supports and services to 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 focussing on their deficits rather than their strengths.

#### Current projects

There are currently 70 disability projects underway supporting 1,433 people around the country. These projects were awarded funding in 2012 and 2013 with project durations ranging from one to three years. The four streams of work are:

## Supporting people to move from institutions

- 23 projects
- ⇒ 281 people

#### Alternative respite provision

- ⇒ 17 projects
- 240 people

#### Supporting school leavers

- 23 projects
- 259 people

#### Capacity building

- 7 projects
- ⇒ 653 people

#### Mental Health Programme

The aim of the Genio Mental Health Programme is to accelerate the availability of recovery-based, cost-effective, individualised supports and services to 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.

#### Current projects

There are currently 75 mental health projects underway supporting 4,290 individuals

around the country. These projects were awarded funding in 2012 and 2013 with project durations ranging from one to three years. The four streams of work are:

#### Supporting recovery / Community living

- 40 projects
- ⇒ 1,960 people

#### Supporting work, education & training

- 9 projects
- ⇒ 330 people

## Supporting families and carers / Alternative respite

- 15 projects
- ⇒ 1,153 people

#### Capacity building

- ⇒ 11 projects
- ⇒ 847 people

#### Dementia Programme

The aim of the Genio Dementia Programme is to develop and test new service models which will improve the range and quality of community-based supports for people with dementia; influence public policy and investment in this area; and build the leadership in the field that is necessary in order to capitalise on the potential of the proposed new Irish National Dementia Strategy. This approach is aligned with government policy, which emphasises the provision of services which support older people to remain at home, living full lives for as long as possible, and supporting families and local communities in this aim.

Due to the nature of the Genio Dementia Programme the projects are consortia-led 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.

#### Current projects

There are currently 12 projects underway within the Dementia Programme. These projects were awarded funding in 2012 and 2013 with project durations of 3 years. The three main streams of work are:

## (i) Develop and test new community supports models (2012)

There are four projects in this stream covering the geographical areas of South Tipperary; Mayo; Kinsale (Cork); and Blackrock-Stillorgan (Dublin). To date they have delivered:

#### Individualised supports

- Models developed
- 466 people provided with individualised supports
- 28,193 hours delivered

#### Training and education

- Models Developed
- 85 sessions delivered
- ⇒ 738 attendees

#### Dementia awareness

- Models Developed
- 134 sessions delivered
- 3,969 attendees

#### Assistive technology

- Models developed
- 52 people in receipt of assistive technology

#### (ii) Develop an integrated care pathway in the acute sector (2013)

- 3 projects St. James's Hospital (SJH); Mercy University Hospital Cork; Connolly Hospital and Local Health Office Dublin NW.
- Catchment areas of North & South Dublin and Cork.

## (iii) Develop individualised supports for persons with complex needs (2013)

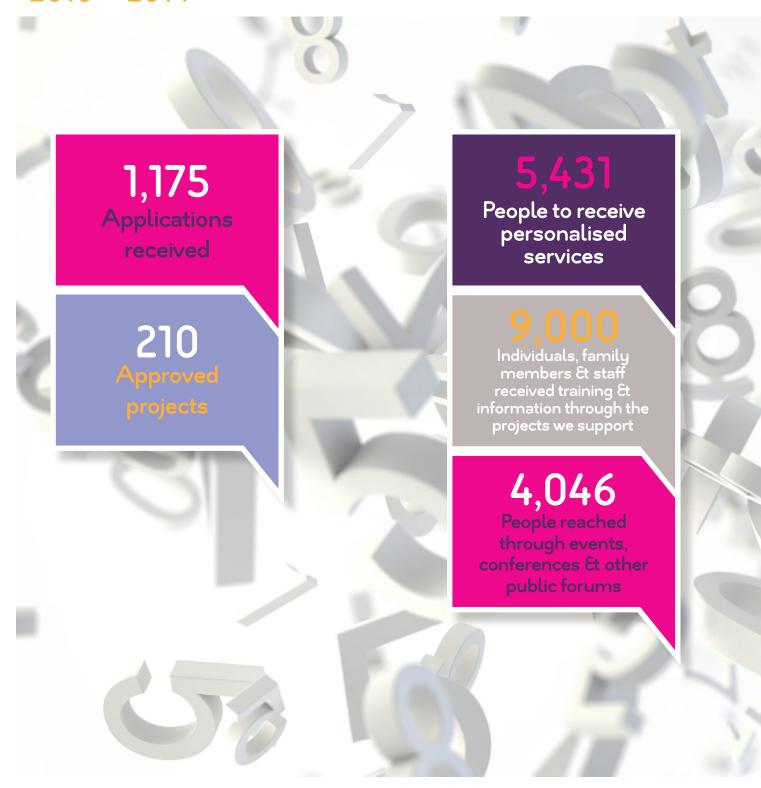
- 5 projects Louth Age Friendly Dementia Consortium; Carlow / Kilkenny Service Providers Forum; Mallow Crystal Consortium; Roscommon Dementia Friendly Community Group; Leitrim Day Hospital Consortium.
- Approximately 180 people.

## Freedem Living - films on positive cognitive health

In addition to the 12 projects supporting individuals and communities across the country, Genio provided funding to an information-based project in 2012.

This is a series of 10 animated films addressing common concerns about memory loss and dementia. They were developed by researchers in Trinity College Dublin with support from Genio in a bid to allay fears about memory loss, promote brain health and tackle the stigma associated with dementia and they are now a valuable resource in the wider field of dementia education in Ireland and abroad. The films can be viewed at www. freedemliving.com.

## By the numbers 2010 - 2014





## Projects supported by Genio 2010 – 2014

Since 2010 innovation funding has been awarded to 210 projects across Ireland through the Genio Trust





Innovation funding is released on a competitive basis to encourage innovation & cost-effectiveness. In 2014 8 projects were awarded funding through the Genio Dementia Programme.

Innovation funding (primarily Government health innovation funding through the HSE) is allocated through the Genio Trust and is designed to be a catalyst in facilitating change in how health and social care services are delivered. The financial support is important to fund the transition from traditional service models to one which provides individualised supports to those who need them.

The criteria attached to the funding also incentivises the reconfiguration of the human and financial resource from the traditional service towards the provision of individualised supports. Funding rounds have been run annually since 2010.

The criteria against which applications for funding are evaluated were developed through a process that commenced in 2009.<sup>1</sup>

<sup>1</sup> Genio (2009) Disability and Mental Health in Ireland - Searching out Good Practice. www.genio.ie/files/Genio\_Report\_2009\_Disability\_and\_Mental\_Health\_in\_Ireland.pdf

Over 110 stakeholders (including people with disabilities and mental health difficulties and representatives of relevant statutory, nongovernmental and academic organisations) were interviewed and a review of relevant documentation on quality and standards was conducted in order to develop criteria that could be used to identify individualised, cost-effective initiatives across Ireland. They have proved robust in clarifying for applicants what type of work will be supported and in identifying the applicants who are likely to be successful. They have been modified continually based on the experience of funding projects and feedback from stakeholders. The criteria are listed in Appendix 3.

#### Innovation funding process



In 2014 eight projects were awarded funding through the Genio Dementia Programme.

#### 1. Priority setting

Each year funding priorities, which reflect national policy are agreed with the Health Service Executive, the Department of Health and the Atlantic Philanthropies. This process informs the funding streams available for application. In 2013-14 we held a funding round in dementia which focused on two specific streams:

- ⇒ Integrated care pathways (ICP)
- Individualised supports in the community

#### 2. Designing and publicising

Online applications for the different funding rounds were designed and published through www.genio.ie along with the criteria and supported by relevant guidelines, FAQ and help sections. Applications were invited in November 2013 by Genio through the national press, information seminars, social media and direct email notices to individuals, agencies and relevant coalition and umbrella groups.

#### 3. Evaluating applications

A total of 27 applications were received by the closing date. All applications were evaluated by Genio against the agreed criteria. Nine applicants were shortlisted and invited for interview in order to gain greater clarity over specific issues in their application.

The applications which most closely met the criteria were submitted for consideration to the Genio Trust Monitoring Group for recommendation to the Board of Trustees.

## New projects awarded funding in 2013-14\*

Organisation	Project Title	Project Description	Funding period (years)	Location	Funding awarded
Mercy University Hospital Project No. 3168	Cork Integrated Dementia Care Across Settings (Cork-IDEAS)	Providing integrated care for people with dementia who may need hospital admission.	3	Cork	€498,500
St. James's Hospital (SJH) Project No. 3167	Development of an integrated care pathway for people with dementia	Integrating care for people with dementia across the Dublin South Inner City community & St. James's Hospital in a person-centred way.	3	Dublin	€500,000
Connolly Hospital and Local Health Office Dublin NW Project No. 3171	Integrated Care Pathway for People with Dementia	Developing an integrated care pathway between the acute hospital & community services specific to the needs of all People with Dementia.	3	Dublin	€500,587
The Crystal Consortium NW Project No. 3181	The Crystal Project	Facilitating individualised & integrated support for people affected by dementia living in Mallow & the surrounding hinterland.	2	Cork	€100,000
Carlow / Kilkenny Service Providers Forum Project No. 3180	Memory Matters - Community Component	Developing innovative home & community based support, alternative respite models & maintaining social connectivity.	2	Carlow/ Kilkenny	€100,000
Leitrim Day Hospital Genio Consortium Project No. 3186	Community Outreach Dementia Project Leitrim (COPL)	Setting out an integrated pathway for people with dementia & their carers from acute/community services, day hospital & home.	2	Leitrim	€100,000
Louth Age Friendly Dementia Consortium Project No. 3175	Flourishing with Dementia (FwD)	Improving the experiences of 35 people with complex dementia-related challenges; supporting people to flourish in the community.	2	Louth	€100,000
Roscommon Dementia Friendly Community Group Project No. 3183	There's No Place Like Home!	Promoting innovative & creative ways of supporting people with dementia to remain in their own home.	2	Roscommon	€100,000
* The funding awarded to projects will be released from the Trust on the basis of progress achieved over the course of the funding period (2-3 years)					

#### 4. Monitoring Group and Trustees

The Monitoring Group consisted of:

- Tom Costello, Programme Executive Ageing, Atlantic Philanthropies.
- Madeleine Clarke, Founding Director, Genio.
- → Teresa Kilmartin, Director, Symbio HR Solutions; Member of the Board of Genio.
- Noel Mulvihill, Assistant National Director for Older Persons, Health Service Executive.

The Monitoring Group reviewed the shortlist submitted and made their recommendations to the Board of Trustees.

#### The Board of Trustees are:

- Prof Brian MacCraith (Chair), President Dublin City University.
- → Dr Ruth Barrington, former Assistant Secretary of the Department of Health and Children.
- Dr Edmond Molloy, Chairperson, Mental Health Reform; Director of Advanced Organisation.

The Trustees reviewed the recommendations and made the final decisions regarding the funding awarded to projects.

#### 5. Project commencement

Following the decision of the Trustees, projects were informed and discussions were undertaken regarding commencement dates and other preparations. Detailed terms and conditions were prepared for each approved project to sign. Genio uses a performance-based funding model. Regular monitoring and support of funded projects takes place over the life of the project where the outputs and outcomes of each project are recorded. Funding is released on the basis of progress achieved.

See the Genio Trust Annual Report 2013-2014 for more details.





A key priority for Genio is building skills and leadership amongst individuals, families and those who have a role to play in supporting people who are disadvantaged to live full lives in their communities.

In addition to information and training provided through the projects we support, Genio also provides information and training directly to individuals, families and service providers. From July 2013 – June 2014 over 1,346 individuals, family members and staff received information and training throughout Ireland across the three sectors in which we currently work - disability, mental health and dementia.

Our skills and leadership building initiatives are focused on Supported Self-Directed Living (SSDL); a framework Genio has been developing. This is based on the concept that SSDL is achieved when individuals, with the necessary support, are able to choose, pursue and achieve 'a good life' similar to others in their society.

Genio's Skills and Leadership Programme comprises two elements:

- The delivery of formal training in evidence-based practice.
- The facilitation of collaborative learning and practice development.

#### Formal training

#### **Enabling Excellence Programme**

The 'Enabling Excellence' programme (previously known as 'Endeavour for Excellence') commenced in both Dublin and Limerick in February 2014, with 100 participating in Dublin and 73 in Limerick, representing a total of 42 disability and mental health organisations. In addition to the trainees, a further 50 senior managers attended the first two days of each training in order to receive a basic introduction.

Through EE, trainees are guided as they support identified individuals to work through a series of steps that result in plans and actions that address their most fundamental needs.

The training will conclude in September 2014. To date feedback has been very positive and demand for related training continues to be high.

A parallel development programme commenced for leaders, referred to as 'Supported Self Directed Living (SSDL) Leaders'. This programme was delivered in both Dublin and Limerick. Leaders in each group collaborated as strong 'communities of practice' and it is anticipated that they will continue to connect with one another for the purpose of on-going professional development beyond the life of the training through an 'SSDL Leaders' Forum'.

### Individuals who use services and their families

Genio's efforts to ensure that family representatives are informed and able to participate in the development of new responses to disability and mental health have included the delivery of three one-day workshops on SRV (Dublin, Cork and Galway) involving around 150 people. As a consequence of these developments, there are now a number of people in the family domain who are able to engage as equals with service providers and other stakeholders in deliberation about good practice, as well as to spread awareness among other families.

## Collaborative learning and practice development

#### Learning communities

Although the evidence base for what works best is growing stronger all the time, we recognise that there remains much to be learned from ongoing demonstration and innovation. Towards that end, we facilitate a range of 'learning communities' or 'communities of practice' through which emergent learning can be captured and applied. These include the following:

- → The SSDL Practitioners' Forum a community of practice for graduates of the Endeavour for Excellence and Enabling Excellence training programmes.
- ⇒ The SSDL Practice Leaders' Forum a community of practice for graduates of the Endeavour for Excellence and Enabling Excellence Practice Leaders' training programmes.

- ⇒ The SSDL Management Leadership
  Forum a community of practice for
  the senior managers of organisations
  implementing initiatives related to the
  Endeavour for Excellence, Enabling
  Excellence, and other high-quality SSDLrelated training programmes.
- → The SSDL National Reference Group

   a learning community comprising
  relevant stakeholders from the disability,
  mental health and dementia sectors
  who are committed to identifying and
  disseminating good practice and building
  cross-sectoral momentum for change.
- ⇒ The Dementia Learning Network a learning network designed to provide opportunities to learn about how to provide community-based supports for people with dementia and their carers in a cost-effective, integrated way.

#### **Inter-Project Learning Days**

One of the most important elements of the Skills and Leadership programme is the collaborative learning and practice development through Genio's 'Inter-Project Learning Days', which sees representatives from Genio-supported projects come together to share learning and engage in practice critique.

From July 2013 to June 2014, nine interproject learning days were organised at which over 100 people attended. We also supported projects and other partners to set up local or sectoral communities of practice in accordance with their specific requirements.

#### **Evaluation Workshops**

We ran two Evaluation Workshops during the course of the year, which were designed to provide attendees with an introduction and the tools to undertake an evaluation of their work. These workshops were attended by 40 people including representatives from Genio-supported disability, mental health and dementia projects.

#### Online resources

In addition to formal training and collaborative learning we are working to grow and develop our online information resources. We were delighted to introduce The Information Hub in 2014 - www. informationhub.ie - a dedicated resource website provided by Genio which brings together publications, multimedia and events for anyone with an interest in disability, mental health or dementia. The Information Hub was developed in response to an identified need for a convenient way of finding and sharing useful resources which has emerged across the three areas we currently work in.



While information on Genio developments will always be shared on the Genio Website www.genio.ie, Genio is providing The Information Hub as a standalone online service which is dedicated solely to displaying a directory of resources in a way which is easy for people to understand and navigate.

The collection of resources on The Information Hub are currently related to one of three areas: disability, mental health

or dementia. The website contains relevant publications including books, papers and reports, legislation and policy, or news and magazines. Also available are relevant multimedia links including websites, slides, podcasts and videos and details of upcoming, related events.

The Information Hub will be under continual growth and development. We hope that visitors to the website will participate in growing the collection by completing an online form on the website to suggest publications, multimedia or events that might be featured.

#### **National Events**

## Reforming Social Services through Public Private Partnership

We hosted a national event 'Reforming Social Services through Public Private Partnership' in October 2013. This event brought together stakeholders from the public, private and non-profit sectors to focus on how social investment can be harnessed to refocus large public service expenditure programmes to achieve better outcomes more cost-effectively for those in need. We welcomed participants and delegates from home and abroad including representatives from Government; national and international foundations and philanthropists; the business community; non-profit organisations; families and individuals being supported through Genio; academics and researchers; and other interested parties.

The event was opened by Kathleen Lynch TD, Minister for Equality, Disability, Mental Health & Older People and Chaired by Bairbre Nic Aongusa, Assistant Secretary General, Department of Health.

#### Featured speakers included:

- Kathleen Lynch TD, Minister for Equality, Disability, Mental Health and Older People.
- Robert Watt, Secretary General,
   Department of Public Expenditure and Reform.
- Stephen Mulvany, National Director Mental Health, Health Service Executive.
- ⇒ Pat Healy, National Director Social Care, Health Service Executive.
- Pat McLoughlin, Chair, Genio and CEO Irish Payments Organisation.
- Prof. Brian MacCraith, Chair, Genio Trust and President, Dublin City University.
- Martin O'Brien, Senior Vice President, Atlantic Philanthropies.
- Shay Garvey, Founding Partner, Frontline Ventures.
- Dr Ruth Barrington, Trustee Genio Trust and Chair, Genio International Research Advisory Committee.
- Prof Roy McConkey, Professor of Developmental Disabilities, University of Ulster.
- Dr Eddie Molloy, Trustee, Genio Trust and Chair, Mental Health Reform.

There were also presentations from representatives of Genio and projects supported through the Genio Trust.

#### Quotes from the day included:

"...Genio...have so many successful examples of how resources can be reconfigured to bring practice into line with our national policy."

Kathleen Lynch TD, Minister for Equality, Disability, Mental Health and Older People, Ireland.

"Genio makes real a vision that we have for people with disabilities and instils hope among services that things can be better."

Bairbre Nic Aongusa, Assistant Secretary General, Department of Health, Ireland.

"We very much believe in this model and what Genio are trying to do... we would like to see and very much support anexternion of this model into new areas to see where we can improve service delivery."

Robert Watt, Secretary General, Department of Public Expenditure and Reform, Ireland.

"...to work with Genio to actually draw on that very significant expertise you have... I think there's a real potential for building on that so that we can move forward in a systemic way...we will continue to enjoy the partnership into the future."

Pat Healy, National Director Social Care, Health Service Executive, Ireland.

"Genio has helped us re-focus...
Smart and fresh thinking which is close to the service-user and tailored to real individuals' real needs....this is a partnership which we value...

Stephen Mulvany, National Director Mental Health, Health Service Executive, Ireland.

"The Genio model is a particularly exciting example of how public and philanthropic money can combine together to bring about lasting improvement for people."

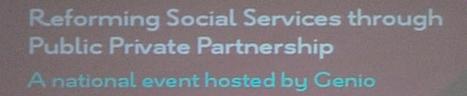
Martin O'Brien, Senior Vice President, the Atlantic Philanthropies.

#### **National Dementia Conference**

We were delighted to host a National Dementia Conference in December 2013, which brought together almost 200 healthcare professionals from Ireland and the UK, family members, academics, carers and volunteers working with and supporting people with dementia. Speakers included:

- Dr Tony Foley, GP, Kinsale.
- Prof. John Keady, University of Manchester.

- ⇒ Dr Sabina Brennan, NEIL Programme.
- Prof. June Andrews, University of Stirling.
- Dr Suzanne Cahill, Trinity College Dublin.
- Claire Bamford, Newcastle University.
- Cathy Byrne and Angharad Langford, Family Support Services, Brothers of Charity, Galway.







Genio undertakes and commissions research and evaluation to measure the impact of our work and the projects we support. We do this in order to inform policy, best practice and implementation in the areas within which we work.

The Genio Research & Evaluation Programme is dynamic and responsive to opportunities which arise within our work. Findings from our research are made public and disseminated to service commissioners and policy makers; used to inform advocacy; and to refine our innovation funding strategy.

Within Genio we monitor the progress of all the projects we support against outcomes agreed at the commencement of the funding period. Three to four onsite visits usually take place over the life of the project where progress is recorded and information and support is offered to projects facing challenges. The results are aggregated in order to measure the overall impact of each Genio funding stream.

In addition, we commission independent research on a competitive basis, overseen by an International Research Advisory

Committee, in specific areas such as moving to independent living, alternatives to group-based 'day services', and new respite services. Evidence is usually gathered from a number of Genio-supported projects related to the specific area of research, and where relevant, other programmes not directly supported by Genio which can usefully inform the overall findings. Three such studies are described here

# An evaluation of personalised supports to individuals with disabilities and mental health difficulties

Prof. Roy McConkey and his colleagues in the University of Ulster and Trinity College Dublin (TCD) were commissioned to conduct an evaluation which 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 views of senior managers of each project were also sought. Data was collected at three time points to capture changes over time for these individuals as they were supported to move to more independent lives in the community. In addition, the key worker for each participant was interviewed along with a family member where available.

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. All of the

participants received individualised supports and most moved from institutional to more independent settings in their communities. Using quantitative and qualitative methods, a range of measures of individual outcomes were obtained, along with data on servicelevel inputs and processes. Data on direct costs were also measured which, combined with the data on outcomes provide an assessment of cost-effectiveness of the interventions across the various sites. The three data collection points over 12-18 months captured change in these measures over time providing information on how outcomes for these individuals change as they move. The key findings showed that:

- Personalisation produces better outcomes than congregated care.
- Quality of life improvements are evident for those who move from congregated care.
- The costs of personalised support and accommodation are considerably lower than those for people in congregated settings, even though some people in personalised arrangements have the highest costs within the sample.
- Group homes do not offer personalised accommodation or support – this has implications for how future deinstitutionalisation is carried out.
- Relatives initial concerns are often not borne out.
- Personalised housing and support options are feasible to implement in Ireland.
- This work takes time to get the optimum outcomes for individuals.

The findings from this evaluation were published in December 2013 and is available to download at <a href="www.genio.ie/multimedia/publications/research-reports">www.genio.ie/multimedia/publications/research-reports</a>. A paper drawing on the findings of one part of the study was published in the journal Administration . A fourth data uplift from the participants is being conducted in 2014 and the findings will be published in 2015. This will provide a longer-term evaluation of the impact of personalised supports on individuals who move to independent living.

# Evaluation of projects supporting individualised opportunities for young people with disabilities

In 2012 the Work Research Centre was commissioned to evaluate projects, which were awarded funding by Genio to support new ways of meeting the work, education, training and recreation needs of young people with disabilities (in particular school leavers) that is mainstreamed and located in 'real' community settings. 15 projects are involved in this research and a mixed methods design was implemented over a 12 month period from December 2012, involving both qualitative and quantitative approaches.

The summary findings have been published at <a href="https://www.genio.ie/multimedia/publications/research-reports">www.genio.ie/multimedia/publications/research-reports</a> and the full report is due for publication in September 2014.

#### The key findings show that:

Mainstream community based activities are central to the success of projects in the eyes of participants.

- The new approaches to service delivery and organisation were highly valued by participants.
- Project costs were generally lower when compared to comparable projects.



## Genio Dementia Programme - Evaluation of Year 1

Eamon O'Shea and Edel Murphy, Irish Centre for Social Gerontology, NUI Galway were commissioned to examine the workings of the Genio Dementia Programme in 2013, the first year of operation, and its impact in relation to the public awareness of dementia, diagnosis, community-based supports, integrated provision and sustainability. The report also covers the relevance and implications of the Genio Dementia Programme over the coming years for public policy and its role in heralding and showcasing a new, person-centred approach to dementia care in Ireland.

This evaluation has identified several issues to consider for future policy for dementia care in Ireland and in supporting the implementation of the National Dementia Strategy:

- "The current policy frame sees dementia" in largely biological terms. The policy frame that underpins the Genio Dementia Programme is different: the emphasis is on the collective and social within a community-based environment; capabilities, assets and inclusion are the principles underpinning the approach. Reconfiguring the paradigm for dementia in Ireland in this way would allow for the potential of the upcoming strategy to be fully realised, thereby becoming genuinely liberating for people with the disease and their families. An alternative policy frame would not necessarily cost more to develop and implement, but it would help establish the primacy of the person with dementia in the decision-making process." (p.39)
- ⇒ The programme is showing that "... bringing together all the interested parties is possible, and is a necessary, if not sufficient, condition for changing the culture and organisation of care." (p.40)
- "Replacing capabilities with risk would allow the potential of people with dementia to be realised during all stages of the disease, particularly in the early stages of the illness. People with dementia have physical, emotional and spiritual needs that require nurturing, through individualised supports, if the various dimensions of personhood are to be realised. Sometimes this means taking changes with care structures and care processes that allow people with dementia to live as normally as possible, in flexible, accessible and familiar



environments that allow capabilities to be maximised. For the most part, people with dementia should live in their own homes where images of self and identity are easier to preserve in the face of ongoing cognitive decline." (p.40)

#### Main conclusions:

The objective of the programme – to develop and test new service models that might improve the range and quality of community-based supports for people with dementia – has largely been met.

The new service models are in place and "the lives of people with dementia have improved in all sites as a result of the investment" (p.39) www.genio.ie/multimedia/publications/research-reports.



#### **Monitoring Projects**

Genio has a comprehensive monitoring system for all Genio-supported projects, where progress reports and data are collected regularly to track progress towards agreed goals and outcomes. This information is gathered with support from onsite visits to the projects by the Genio team, usually three to four times a year.

In 2013 we designed and developed a new on-line reporting system for projects, which allows the collection of both qualitative and quantitative information. Reporting forms are tailored to the specific goals and activities of each grantee so that their unique progress can be tracked. Detailed case studies of individuals, families and services are also gathered to provide a further insight into the impact achieved.

A database has also been designed and developed to collect detailed information and outcomes on people with dementia and their carers over time who are being supported through the Genio Dementia Programme. This database will provide a rich data resource that will be unique in Ireland in terms of its scale.

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.

To date, 117 completed disability and mental health projects have been scored, which generated the following results:

- 85% of projects to date have achieved or exceeded their project aims
- 15% of projects have not yet achieved all of their project aims



We have a busy year ahead as we continue to support projects across Ireland; expand our Research and Evidence programme; and grow and strengthen the numbers of people accessing skills and leadership development opportunities.

#### Innovation funding

We look forward to the development of the new projects awarded funding under the Genio Dementia Programme focussing on integrated care pathways in the acute hospital sector and individualised supports in the community.

Genio has opened a new round of innovation funding to mental health projects and funding will be awarded to projects pending the evaluation process in the latter half of 2014. The funding streams include supporting recovery; supporting work; supporting families and carers; and capacity building. Updates will be published on www.genio.ie.

#### Research and Evidence

Genio has commissioned a comprehensive range of research and evaluation studies,

several of which will be published in late 2014 and 2015. These include:

- ⇒ Prevalence and Projections of Dementia in Ireland, 2011 - 2046.
- → An evaluation of Year 2 of the Genio Dementia Programme.
- ⇒ A follow-up study on personalised supports for people with disabilities and mental health difficulties.

Genio has commissioned a number of briefing papers to provide accessible overviews of key areas relating to the development of dementia services which are due for through the latter half of 2014 and into 2015. These include:

- → An exploration of the diagnosis of dementia; what the current practice is in Ireland; a description of common standardised instruments for cognitive assessment; an overview of practices in other parts of the world; and based on the evidence, some actions for consideration.
- ⇒ An exploration of the Dementia Advisor Role which focuses on the provision of information to people with dementia and their carers; the signposting of the dementia journey; and the provision of support on that journey.

These papers will help inform the development of the National Dementia Strategy which is due to be published in December 2014.

#### Building skills and leadership

Drawing on our experience with the Endeavour for Excellence and Enabling

Excellence training, we are currently working to develop training in Supported Self-Directed Living (SSDL); a framework Genio has been developing based on the concept



that SSDL is achieved when individuals, with the necessary support, are able to choose, pursue and achieve 'their good life' to a similar extent to others in their society. Different courses and training options will be developed for individuals, families, frontline practitioners and management in service providing organisations. An SSDL Train the Trainer Course will also be developed to prepare suitable candidates from service providing organisations to deliver in-house training in. It is anticipated that delivery of the new SSDL training will commence in 2015.

Genio's efforts to ensure that family representatives are informed and able to participate in the development of new responses to disability, mental health and dementia continue.

#### **Events**

In November 2014 we will host our first regional seminar in Donegal aimed at projects supported by Genio, project partners including representatives from the local HSE area and other interested parties. Representatives from the Donegal, Sligo and Leitrim region will be invited to share outcomes and learning gleaned from projects supported by Genio in these areas. We hope to roll out further regional seminars around the country in 2015.

In December 2014 we will also host our annual National Dementia Conference bringing together healthcare professionals from Ireland, the UK, the US, family members, academics, carers and volunteers working with and supporting people with dementia. This conference will focus on three key themes - 'The Lived Experience', 'Value and Values', and 'Collective Approaches to Change'.

#### 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 with disabilities, mental health difficulties and dementia to live full lives in their communities.





## Appendices

#### Appendix 1 - Genio Boards, Committees & Team 2013

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 Members

- → Pat McLoughlin, Chairperson, Genio; Former CEO, Irish Payment Services Organisation; Former Chairperson, Local Government Efficiency Implementation Group.
- Madeleine Clarke, Founding Director, Genio.
- Dr Cathal Coleman, Lecturer, Department of Politics, University College Dublin; IT Consultant.
- Teresa Kilmartin, Director, Symbio HR Solutions.
- Patrick McGowan, Expert by Experience; Lecturer, Dublin City University; former Director of Advocacy, Irish Advocacy Network.
- → Geraldine Ruane, Chief Operating Officer, Trinity College Dublin.
- Dr Iognáid (Iggy) O'Muircheartaigh,
   Uachtarán / President Emeritus, NUI Galway.
- Barney Whelan, Director of Communications and Corporate Affairs, An Post.

#### Genio Trust

- Professor Brian MacCraith, Chairperson;
   President of Dublin City University.
- Dr Ruth Barrington, former Assistant Secretary, Department of Health and Children.
- Dr Edmond Molloy, Chair, Irish Mental Health Reform; Director, Advanced Organisation.

#### Genio Monitoring Group

- Madeleine Clarke, Founding Director, Genio.
- Tom Costello, Programme Executive Ageing, Atlantic Philanthropies.
- Cate Hartigan, former Assistant National Director Disability Services, Health Service Executive.
- Teresa Kilmartin, Director, Symbio HR Solutions.
- Noel Mulvihill, former Assistant National Director for Older Persons, Health Service Executive.
- Martin Rogan, former Assistant National Director Mental Health Services, Health Service Executive.

#### International Research Advisory

#### Committee

The International Research Advisory Committee incorporates expertise across intellectual disability, physical and sensory disabilities and mental health sectors, and also health economics and programme change.

#### Members:

- → Dr Ruth Barrington (Chair), former Assistant Secretary, Department of Health and Children, Ireland.
- Professor Jerome Bickenbach, Disability Policy Unit, University of Lucerne, Switzerland.
- ⇒ Gail Birkbeck, Strategic, Learning & Evaluation Executive, Atlantic Philanthropies, Ireland.
- Sarah Craig, Head of National Health
  Information Systems, Health Research Board,
  Ireland.
- □ Dr. Bob Illback, President, CEO, & Senior Evaluation Researcher, Reach, Louisville, Kentucky, US; & Deputy CEO, Headstrong, Ireland.

- Dr. Fiona Keogh, Director of Research and Evidence, Genio, Ireland.
- ⇒ Prof. Philip McCallion, Director of the Centre for Excellence in Ageing & Community Wellness, University of Albany, US.
- Dr. David McDaid, Research Fellow in Health Policy & Health Economics, London School of Economics & Political Science, UK.
- ⇒ Prof. Gerard Quinn, Director of the Centre for Disability Law & Policy, National University of Ireland Galway, Ireland.

#### Dementia Advisory Committee

- Anne Connolly, Director, Ageing Well Network.
- Tom Costello, Programme Executive Ageing, Atlantic Philanthropies.
- → John Dunne, Acting CEO, The Carers Association.
- Dr Kate Irving, Researcher and Lecturer in the Department of Nursing and Human Sciences, Dublin City University.
- → Marie Lynch, Programme Development Manager, Irish Hospice Foundation.
- Noel Mulvihill, former Assistant National Director for Older Persons, Health Service Executive.
- → Maurice O'Connell, former CEO, The Alzheimer Society of Ireland (ASI).

#### Dementia Technical Advisory Group

- Dr Suzanne Cahill, Research Associate Professor of Social Work and Social Policy, Trinity College; Director, Dementia Services Information and Development Centre at St James's Hospital Dublin.
- Hope Leet Dittmeier, International Expert in Social Role Valorisation, Realizations LLC.

- Prof Murna Downs, Chair in Dementia Studies and Head of Bradford Dementia Group, University of Bradford.
- → Prof Caroline Glendinning, Professor of Social Policy, University of York.
- ⇒ Prof. Eamon O'Shea, Personal Professor, School of Business & Economics, NUI Galway.

#### Genio Team

- Madeleine Clarke, Executive Director.
- Hugh Kane, Chief Operations Officer.
- → Dr Fiona Keogh, Director of Research and Evidence.
- Dr Paul Doherty, Leadership Development Manager.
- Tara Doheny, Programme Manager Disability.
- ➡ Elaine Howard, Programme Manager Dementia (P/T).
- → Mary McGuire, Programme Manager Dementia (P/T).
- ➡ Eimear Connaughton, Programme Manager Mental Health.
- Olivia Cosgrove, Research Officer.
- Margaret Flynn, Accounting and Grants Officer.
- Fiona Murphy, Communications Manager.
- Orlaith Potter, Communications and Operations Executive.

#### Appendix 2 - Genio Limited

#### **GENIO LIMITED**

(A company limited by guarantee and not having share capital)

## INCOME AND EXPENDITURE ACCOUNT FOR THE YEAR ENDED 30 JUNE 2014

	2014 €	2013 €
INCOME	1,600,430	1,610,441
EXPENDITURE	(1,630,940)	(1,607,451)
SURPLUS ON ORDINARY		
ACTIVITIES BEFORE INTEREST	(30,510)	2,990
Other interest receivable and similar income	4	8,393
SURPLUS ON ORDINARY		
ACTIVITIES BEFORE TAXATION	(30,506)	11,383
Taxation	1,088	684
SURPLUS ON ORDINARY		
ACTIVITIES AFTER TAXATION	(29,418)	12,067
RETAINED SURPLUS FOR THE YEAR	(29,418)	12,067

#### GENIO LIMITED

(A company limited by guarantee and not having share capital)

#### BALANCE SHEET AS AT 30 JUNE 2014

	2014	2013
	€	€
FIXED ASSETS		
Tangible assets	37,551	37,314
Intangible assets	37,551	37,314
DEBTORS:		
(Amounts falling due within one year)	116,241	271,823
Cash at bank and in hand	4,373	1,448
	120,614	273,271
CREDITORS  (Amounts falling due within one year)	(144,806)	(267,809)
(Amounts falling due within one year)		
NET CURRENT ASSETS	(24,192)	5,462
TOTAL ASSETS LESS		
CURRENT LIABILITIES	13,358	42,776
Deferred income		-
NET ASSETS	13,358	42,776
CAPITAL AND RESERVES		
Revenue reserves account	13,358	42,776

# Appendix 3 – Criteria for assessing applications to the Genio Trust

Applications in all the grant streams are assessed against the following key criteria:

- 1. Project description highest scores will be for those applications which:
  - a. clearly describe the aims and activities and number of individuals to be supported.
  - b. describe responses that are consistent with relevant policy.
  - c. aim to support individuals in a way that builds on their strengths and where supports are planned and delivered on the basis of a consideration of the wider needs and potential contributions of the person, moving away from a focus on deficits.
  - d. provide individual rather than group-based responses.
  - e. are based on supports and settings which are chosen by the person with a disability/ mental health difficulty/ dementia (or their family or advocate as appropriate).
  - f. are delivered in the community, fostering inclusion and participation rather than in segregated, stigmatising settings.
  - g. use family and community supports and mainstream services whenever possible.

- h. are reliant on paid professionals only when necessary.
- i. articulate a strong vision of reconfigured services to roll this provision out to more individuals and sustain this model into the future
- j. clearly describe the outcomes to be achieved.
- 2. Value for money highest scores will be for applications which demonstrate the strongest cost-effectiveness (i.e. a strong cost benefit ratio) and which include a reconfiguration of resources. The overall application itself must represent good value for money in comparison to other applications.
- Financial and organisational sustainability beyond the life of the grant – highest scores will be for applications with the most robust and detailed sustainability plans, which includes reconfiguration of resources.
- 4. Governance and organisational capacity within the organisation to implement proposal highest scores will be for those applications which can demonstrate the extent of the commitment of the organisation to this work in terms of; competencies within the organisation, strong change management and implementation planning, high-level support in organisation and/or funder and, where relevant, commitment to rollout through the whole organisation.
- 5. Other criteria which are taken into account include the quality of the individual plan (if requested) and the composition of the consortium (if applicable to grant stream).





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