

DOCTRID

DAUGHTERS OF CHARITY
TECHNOLOGY AND RESEARCH INTO DISABILITY



Daughters of Charity
Disability Support Services



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Disability Support Services

RESEARCH TO IMPROVE THE LIVES OF PEOPLE WITH INTELLECTUAL DISABILITY OR AUTISM SPECTRUM DISORDERS

WHAT IS DOCTRID?

DOCTRID, or the DOCTRID Research Institute (DRI) is a network of **scientists, disability service providers, healthcare professionals, industry partners and people with Intellectual Disability (ID) or Autism Spectrum Disorder (ASD)**. It was established in 2010 by the charity RESPECT and the Daughters of Charity Disability Support Services (DoC) to oversee multidisciplinary research into ID and ASD. The 2 main research programmes currently running within the DRI are the €9M ASSISTID Programme (cofunded by the European Commission and RESPECT) and the Michigan State University (MSU)-DOCTRID Hegarty Fellows Programme. Both programmes involve researchers based within DOCTRID partner universities across Ireland, the UK and the US who work closely with the DoC staff and service users.

The DRI, through its dedicated international network of experts has an extraordinary capacity to make a difference in the lives of people with ID or ASD.



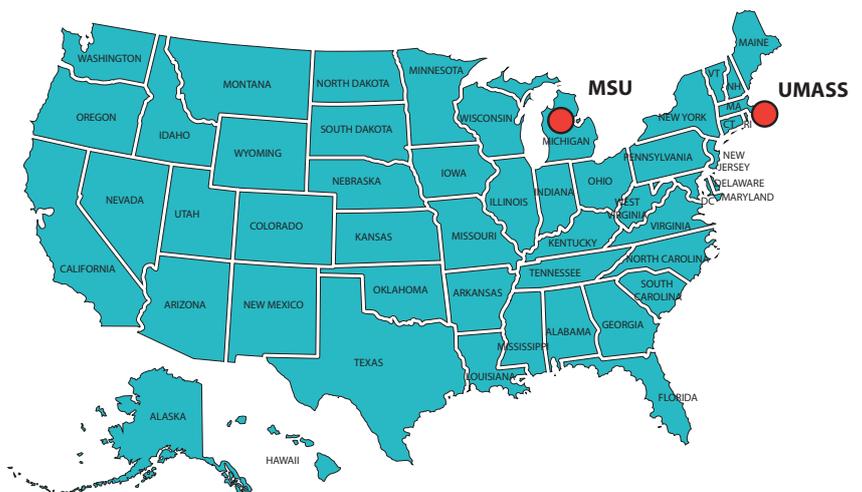
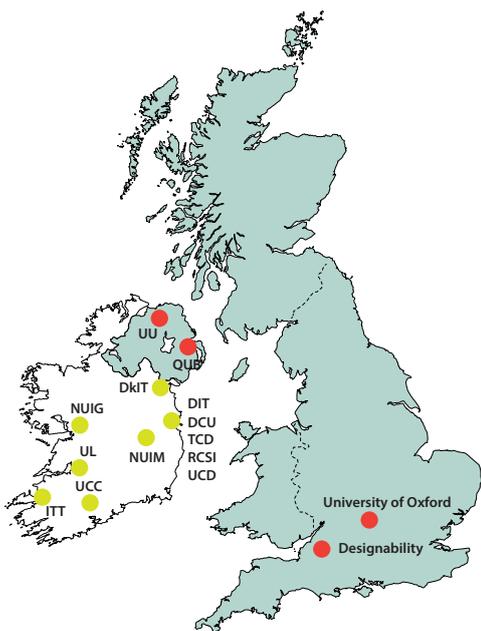
BE A PART OF IT!

DOCTRID NETWORK

The DOCTRID Research Institute is made up of 17 different universities and Higher Institutes of Education from Ireland, the UK and the USA plus the Daughters of Charity Disability Support Services.

The DOCTRID network is one of the world's largest connected efforts to improve life for individuals with Intellectual Disabilities (ID) or Autism Spectrum Disorder (ASD) through innovative research and training. We bring together expert scientists, practitioners, carers and people with ID or ASD from across the globe who share a common commitment to undertake innovative multidisciplinary research.

Multidisciplinary research means that people from different areas of expertise work together to ensure that all research is relevant and practical, e.g. an engineer who wishes to develop a new device will work with an occupational therapist and/or psychologist plus the individual with ID, and their families or carers. **No single discipline can fully understand or resolve the challenges around ID or ASD**, which is why the multidisciplinary research conducted by the DOCTRID Research Institute is so important.



MEET THE TEAM



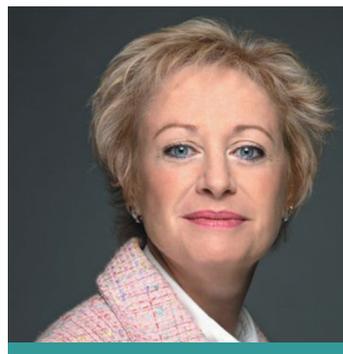
Professor Brian Harvey
Director of Research



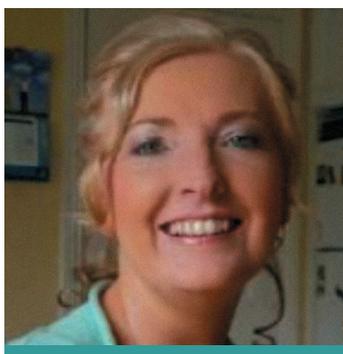
Sr Zoe Killeen
Director of RESPECT



Dr Sheeona Gorman
Programmes Manager



Ms Gretta FitzGerald
Administrative Assistant



Ms Breda Hawkshaw
Operations Financial
Accountant



Mr Alejandro Sotomayor
Photojournalist and Web
Developer



Ms Alie Kwint
Project Consultant

DOCTRID Research Institute



The DOCTRID research office team coordinate and manage research activities within the DOCTRID Research Institute. Currently the 2 main programmes are ASSISTID and the MSU-Hegarty Fellowship programmes.

Why is DOCTRID important?

It is estimated that between 1-3% of the population has an ID with similar prevalence rates for ASD reported in the literature. This means that currently there are ~13 million people with either ID or ASD in Europe. In addition 40-50% of individuals with ASD have an Intellectual Disability.

To date, very little research has been done on how to achieve and maximise social and community inclusion for people with ID or ASD. DOCTRID plans to remedy this and raise awareness of this often marginalised group.

The DOCTRID network partners will conduct the highest quality research to identify best practice and opportunities for inclusion and to devise Assistive Technology solutions to allow people with ID or ASD to participate in society to their fullest potential.

Why now?

Social model of disability. Society has changed in the last 15-20 years; we now recognise that individuals with disabilities have the same rights and opportunities to employment, education and community living as any other member of society. The United National Convention on the Rights of Persons with Disabilities (UNCRPD) requires member states to ensure that all citizens are free from discrimination, have a say in the decisions which affect their lives and access to Assistive Technologies.

People with ID are living longer than ever before. While this is good news, individuals with ID have a significantly increased risk of dementia relative to the general population. We need to better understand how to support these individuals.

The move away from congregated settings. National policy in Ireland and across Europe aims to move people with ID away from congregated settings and into the community. This offers opportunities for meaningful community integration and increased independence. However, the appropriate supports to ensure a successful transition, including Assistive Technology will be vital.

Lack of research. Historically, people with ID or ASD have been an often forgotten group in society. There has been very little research into how to improve their Quality of Life, in particular through Assistive Technologies.



Why is research important?

Research allows us identify the most effective treatments or interventions. Access to a source of evidence based research and practice allows clinicians, health care workers and service providers to progress the standard of care. Research identifies what works and what does not, where there is an unmet need, how best to meet this need and where additional funding should be allocated.

The DOCTRID Research Institute gives people with ID or ASD, parents and service providers the opportunity to participate in studies designed to develop effective evidence-based treatments, technologies and interventions.

With the collaboration of the Daughters of Charity Disability Support Services (DoC) staff and service users we can make a difference.

Through expert rigorous research we can

- Understand and raise awareness of the needs and priorities of the ID or ASD community
- Provide an evidence base to help families, carers and health care professionals to make informed decisions about care, use of Assistive Technology (AT) and other interventions
- Develop new, cost effective and user friendly AT
- Inform policy to change legislation
- Improve independence, choice, opportunities and inclusion for people with ID or ASD
- Reduce levels of care required and assist transition into the community through the use of appropriate AT

Spotlight on....



The DOCTRID Research Institute is leading the way, with the support of RESPECT and the European Union, in ground breaking research into Assistive Technologies through the ASSISTID programme.



ASSISTID

ASSISTID is the name of a €9M research programme which is funded by RESPECT and the European Union over 5 years from 2014-2019. ASSISTID will fund 40 researchers ("Fellows") to carry out individual projects in a range of areas around Assistive Technologies for Intellectual Disability and Autism. They will be based in universities, service providers and industry partners throughout Ireland, the UK and USA.



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MEET OUR NEW ASSISTID RESEARCH FELLOWS!

The first 11 Research Fellows have been appointed by the DOCTRID Research Institute and will begin their research projects from August 2015. All Fellows are encouraged to work with the DoC and will be meeting with staff and service users across the country over the coming months. This collaboration between the DoC and the researchers is vital to ensure a common understanding of the challenges of ID research and the importance of understanding the need and abilities of individuals with ID or ASD. It will provide an opportunity for DoC staff to offer their expertise and experience to contribute to the research outputs and influence the research in a practical way.



Dr Pauline Frizelle
Oxford & UCC



Dr Sean O'Neill
DCU



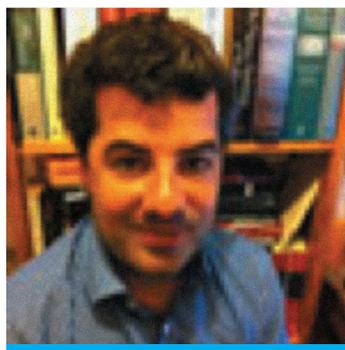
Dr Cathy Dalton
UU & UCD



Dr Bryan Boyle
TCD



Dr Ken Kerr
UU & UCD



Dr Fiachra O'Brolchain
QUB & DCU



Dr June Chen
NUIG



Ram Prasad Krishnamoorthy
DCU



Dr Neha Khetrpal
UCC



Dr Enrique Garcia-Nunez
UCC



Dr Shawn Gilroy
NUIG

The Fellows projects address the following issues of relevance.

- The Ethics of Assistive Technology
- Increasing independence in adults using smartphone prompting
- Creating immersive rooms to promote well-being and reduce challenging behaviour
- 3D Collaborative virtual environments to improve social interaction for non-verbal children
- Using Video Modelling to teach Life Skills
- Computerised assessment of speech development
- Employment readiness training for adults
- Personalised computer based behaviour analysis learning programmes
- Technologically Assessing Language Competence
- Developing interactive toys for children
- A randomized controlled trial to compare high- and low-technology communication devices

We will be funding a further 29 Fellows over the coming months who will be tackling other important research questions relating to how Assistive Technology can improve the lives of people with ID or ASD.

Be sure to check the website (www.assistid.eu) for updates.

WHAT IS ASSISTIVE TECHNOLOGY?

Assistive Technology (AT) refers to devices and tools which allow people to perform many of the tasks of daily living and to participate in social activities, employment and education, increasing independence and wellbeing and improving quality of life. AT can be either low or high tech.



Low Tech

- Wheelchairs
- Grab rails
- Magnifiers
- Specialised seating
- Walking aids

High Tech

- Sensors (wearable/home)
- Communication devices
- Eyegaze control
- Computer based learning
- Virtual reality
- Smartphone/Apps
- GPS-wayfinding

“For people without a disability, technology makes things easier. For people with a disability, technology makes things possible”

Assistive Technology can transform people’s lives and open up a whole new world of opportunity. However it is vital that any new technology developed is **appropriate to the needs and ability of the person, user friendly and affordable**. When these factors are not assessed properly the device or technology can be abandoned, estimates range as high as 30-50% abandonment for AT. This is where the necessity of **multidisciplinary, person centered** research is vital in order to ensure impact and relevance.

The UN Convention on the Rights of the Person with Disabilities recognises the importance of AT-it requires member states to ‘undertake or promote research and development of, and to promote the availability and use of assistive technologies, suitable for persons with disabilities’.

MSU-DOCTRID HEGARTY FELLOWSHIP PROGRAMME

The MSU-DOCTRID Hegarty Fellows Programme is designed to provide training for postdoctoral researchers in the areas of ID or ASD and other neurodevelopmental disabilities. The first cohort of MSU-Hegarty Fellows have completed their 2 year research projects in July 2015. The MSU-Hegarty programme is structured to allow researchers to spend 6 month periods alternating between Michigan State University and their Irish host university. While in Ireland, researchers work with service users and staff at the DoC.



Dr June Chen
MSU & NUIG

Current ASSISTID Fellow at NUIG



Dr Stacy Clifford
MSU & NUIG



Dr Carolyn Shivers
MSU & TCD

Dr June Chen is continuing her work as a Hegarty Fellow into an ASSISTID Fellowship, based at NUI Galway for a further 2 years. She is creating an online tool to provide for training and support in job readiness for adults with ID or ASD. She will be working with DoC TEES to develop this tool to increase employment opportunities for people with ID or ASD.

Dr Stacy Clifford increased our understanding of social inclusion during her time as a Hegarty Fellow. She published a paper in the journal 'Research in Developmental Disabilities' entitled '*Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation*' which highlights the importance of both interpersonal relationships and community participation in achieving real social inclusion for people with ID.

Dr Carolyn Shivers was focused on developing the LifeStory work amongst older adults with ID. This involved using iPads and a suite of apps to create a personalised LifeStory and creating a 'Train the Trainer Manual' for DoC staff. The next phase is to measure and evaluate the effectiveness of LifeStory work through technology in improving communication, social connectedness and quality of life for people with an intellectual disability. This important research is continuing within the DoC.



Pictured at the DOCTRID IV Conference in Belfast are Prof Brian Harvey, Dr June Chen, Dr Geraldine Leader, Prof Michael Leahy, Dr Stacy Clifford & Dr Caroline Shivers.

We would like to thank June, Stacy and Carolyn for their work ethic and dedication to research excellence. They have been excellent ambassadors for the MSU-DOCTRID research programme.

The next 3 Hegarty Fellows will begin their research in September and we will welcome them to Ireland in Spring 2016.



Call for ASSISTID-Marie Curie proposals 2015

FELLOWSHIPS IN INTELLECTUAL DISABILITY (ID), AUTISM SPECTRUM DISORDER (ASD), INTELLECTUAL DISABILITY WITH DEMENTIA

Potential ASSISTID research questions include

- ✓ Benefits of AT to the community-is there an increase in Quality of Life for AT users and/or their carers.
- ✓ Application of existing technology to a new cohort or novel use.
- ✓ Assessment of existing technology.
- ✓ Training tools for health care professionals.
- ✓ What is the cost benefit of AT?.
- ✓ Development of new technology/ interfaces.
- ✓ Review of policy and provision of AT-gaps and future directions.
- ✓ Ethics of AT.
- ✓ Online tools, platforms, online learning.



Deadline: 30th September 2015

Visit www.assistid.eu for more information

THE PEOPLE



DOCTRID

DAUGHTERS OF CHARITY
TECHNOLOGY AND RESEARCH INTO DISABILITY

Get in touch

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